

Fatal Five

Preventable Death in Disability

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 **Bluestone**
*Physician Services*SM



Integrated Care Team



Comprehensive care of folks with disabilities



The Fatal Five

A few disclosures



Fatal Five

- Identify and discuss the top 5 conditions leading to preventable death in patients with developmental disabilities
- Share tips, tricks and queues to monitor in our vulnerable populations
- Compare and contrast how the “top five” list could apply to other vulnerable populations

What are the **Fatal Five**?

Aspiration

GERD

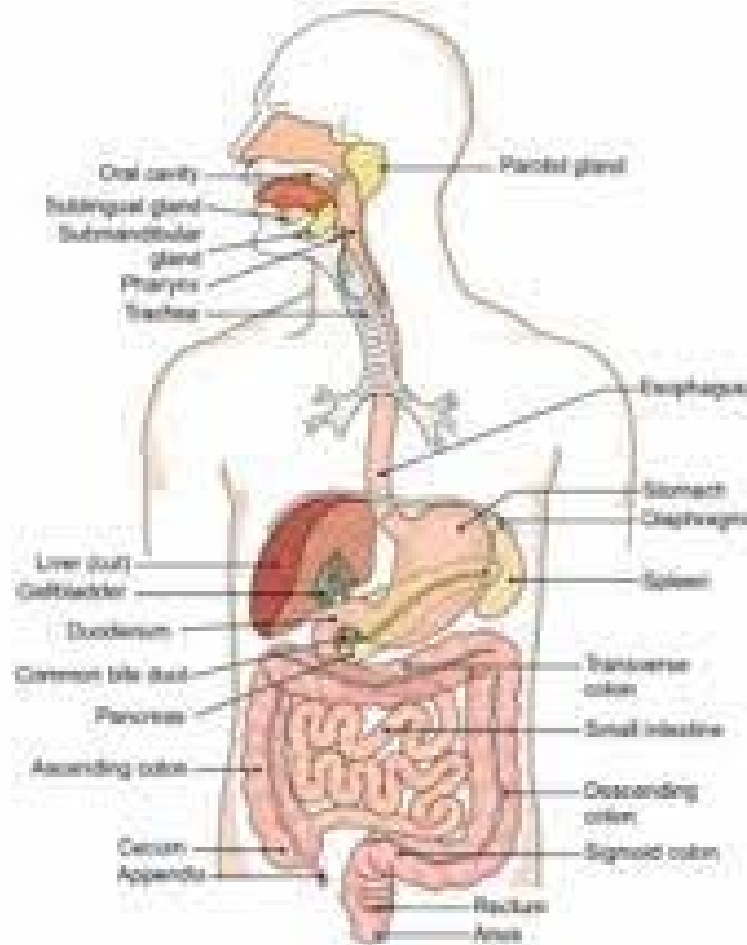
Constipation

Dehydration

Seizures



GI tract



GI tract

The design has some serious flaws!

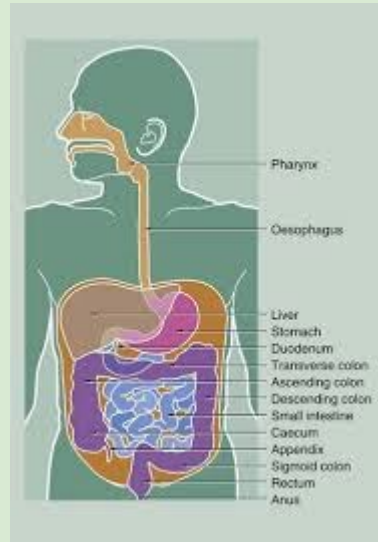
Nothing gets to enter without first crossing the airway

It is filled with noxious chemicals from which it is not well protected

It is gravity-dependent

The function is affected by $\frac{2}{3}$ of the meds on the market

It is impacted by everything: meds, stress, physiology, position, nutrition, hydration



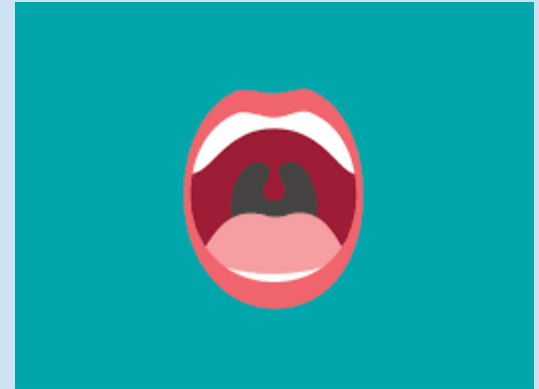
Q: Approximately what percentage of people with IDD do you think experience swallowing issues?

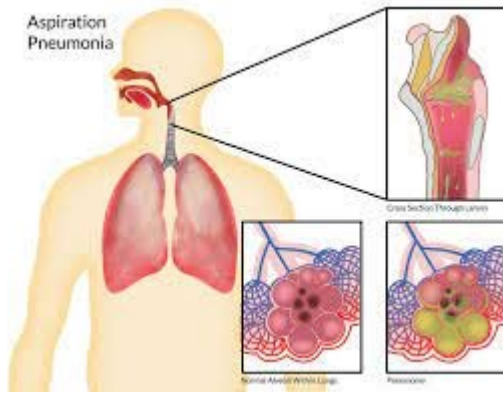
- a. 16%
- b. 27%
- c. 49%
- d. 94%



Q: Approximately what percentage of people with IDD do you think experience swallowing issues?

- a. 16%-- general population
- b. 27%--elderly population
- c. **49%--ID/DD** and Alzheimer's
- d. 94%--ID/DD per 2009 study





Aspiration

Aspirate (pronounced AS-pih-rayt) refers to the act of withdrawing the fluid, tissue, or other substance through a needle. It also refers to the **accidental breathing in of food or fluid into the lungs**. This can cause serious problems, such as pneumonia and other lung problems.

Aspiration

MOST COMMON CAUSE OF DEATH in institutional settings, including nursing homes and large group care settings for person with IDD.

Often begins subtly and damages increasing areas of the lungs. Aspiration pneumonia is a common discharge dx following hospitalization.

Other factors may lead to aspiration are poor body positioning, particularly in individuals who cannot control their own movements and behavioral issues related to eating.



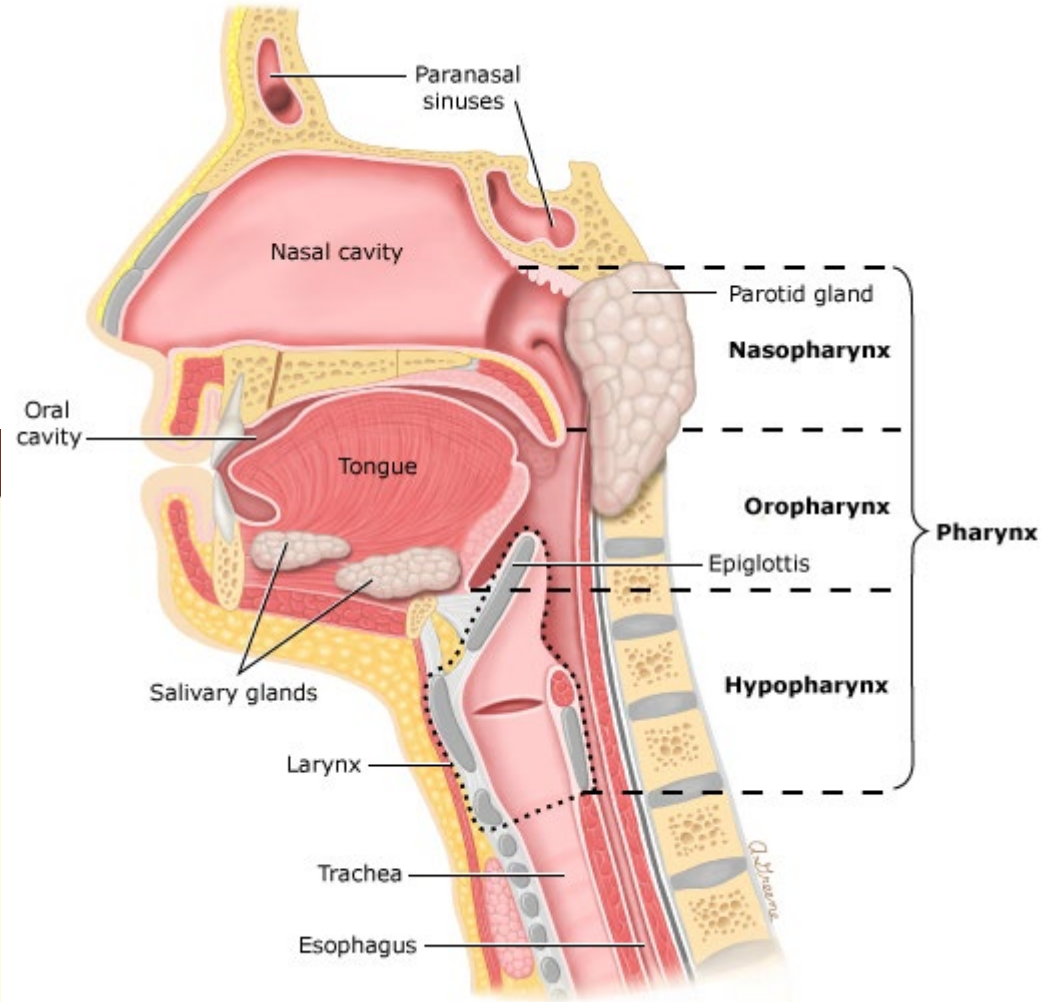
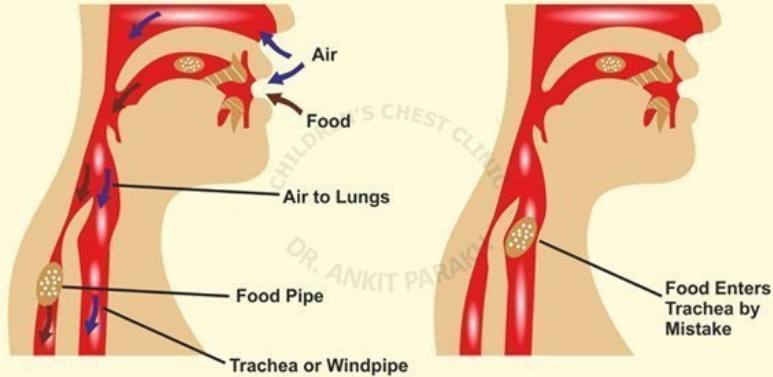
Common medical and behavioral factors that can increase risk of aspiration

- Dysphagia, or difficulty swallowing
- Difficulty controlling head or neck muscles
- Mobility limitations that prevent sitting up straight
- Impaired consciousness or awareness
- GERD, or Gastroesophageal reflux disease
- Eating too quickly or putting too much food in one's mouth
- Dental problems that prevent adequate chewing
- Anatomical variation such as a small airway or a large tongue



Anatomy of the head and neck

ASPIRATION



Getting in trouble with swallowing

Aspiration is about swallowing only 25% of the time

Look at the following:

Before it goes down

As it goes down

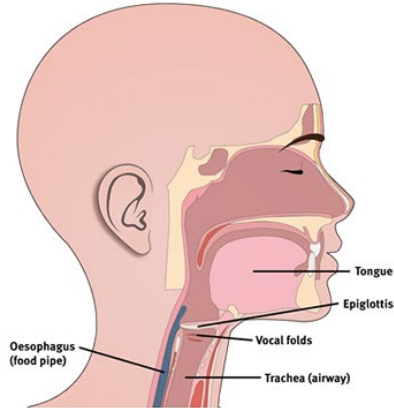
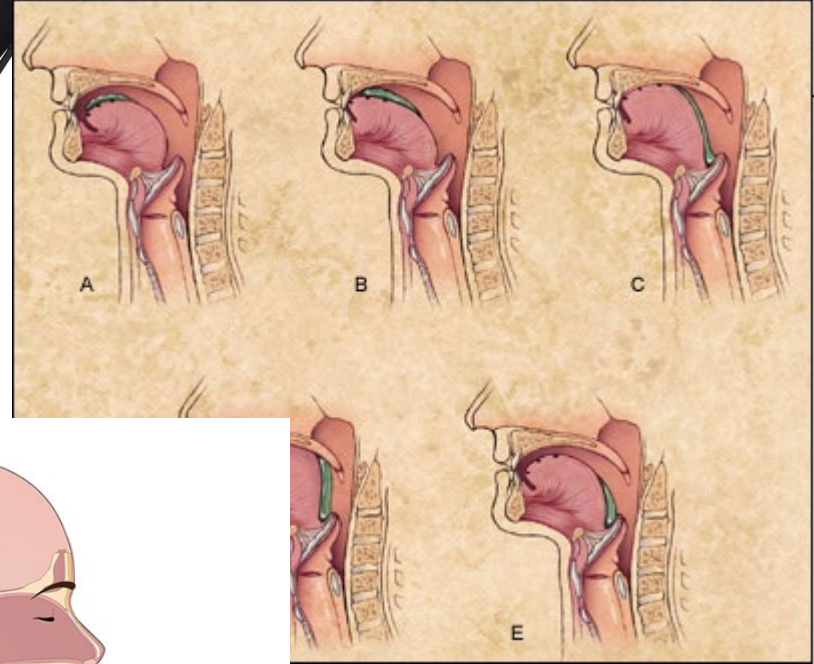
Does it go down

Does it get out of the stomach

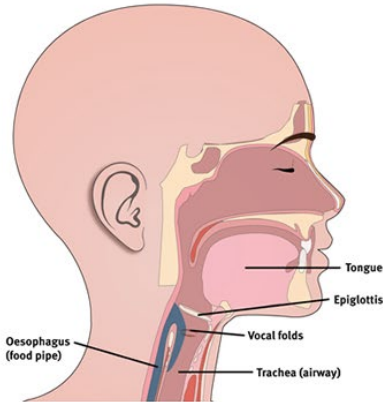
Does it come out the other end



Aspiration

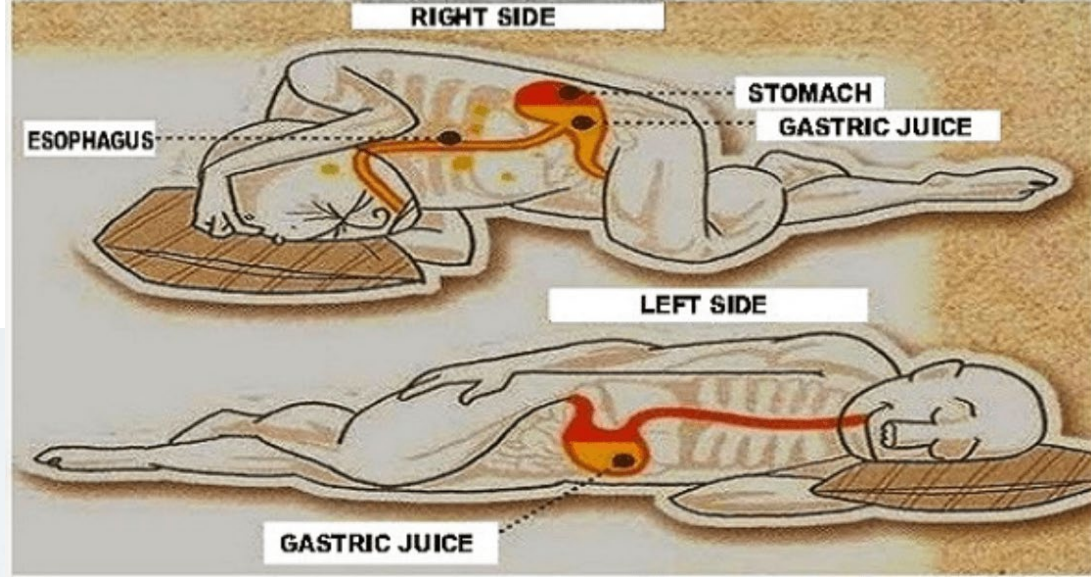


Normal swallow



Aspiration

Positioning for emptying



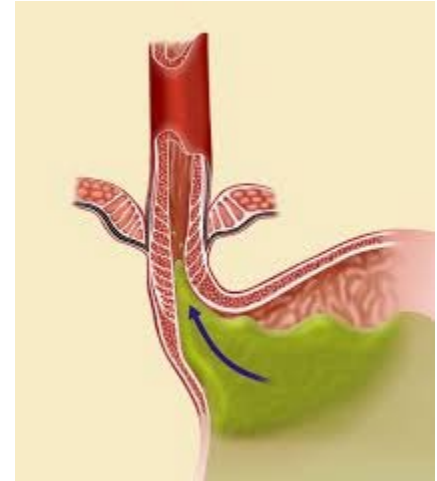
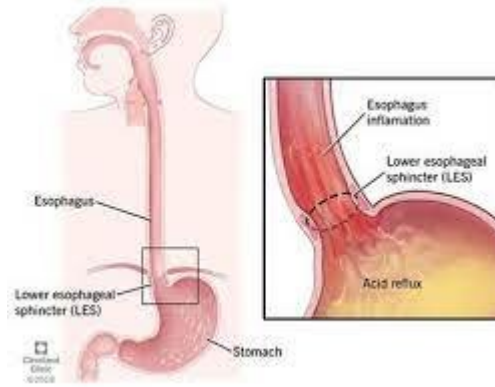
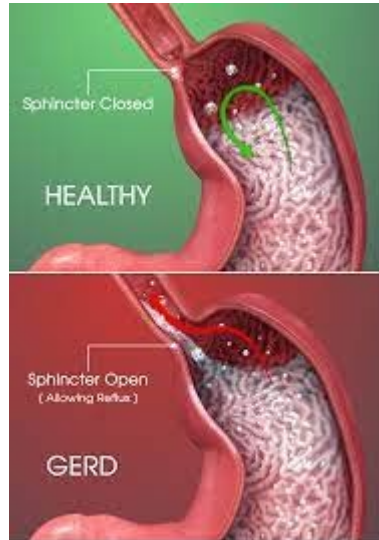
Considerations

- Treat **esophageal spasms**
- Address **dental problems**
- A **swallow study** can help identify the level of aspiration risk a person has.
- An **occupational therapy** assessment may identify adaptive equipment to help them eat more comfortably and with lower risk.
- **Modified diets**
- Use a **thickener** in beverages.
- **Speech therapy** may improve a person's control over their tongue and throat muscles.
- Evaluate the use of **medications** such as sedatives, opioids, and muscle relaxers
- **Behavioral interventions** may address eating too much or too quickly.
- In severe cases, individuals may require more significant **medical intervention** such as surgery, oral suctioning, or a feeding tube.



GERD

Back up of stomach contents, including acid, into the esophagus. Often undiagnosed until major harm has been done to the bottom of the esophagus.



GERD

What percentage IDD have dx of GERD (Reflux)?

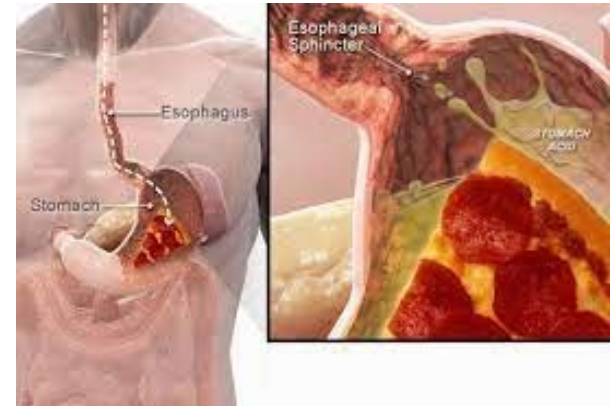


GERD

What percentage IDD have dx of GERD (Reflux):

50%

(general pop 10-20%)



GERD-Risks

Meds that cause constipation also contribute to GERD.

Overweight (particularly when the carry excess around abdomen or have belts/clothing that is too tight) have a higher risk of GERD.

Ill advised dietary choices

Immobility

Improper positioning also contributed to incidence.



GERD-signs

- A burning sensation in your chest (heartburn), usually after eating, which might be worse at night.
- Chest pain.
- Difficulty swallowing.
- Regurgitation of food or sour liquid.
- Sensation of a lump in your throat.



Signs not recognized: pica, hands in mouth, agitation within 30 min of eating, agitation/restlessness in middle of night, refusing meds

Clinical signs: low hgb/hct/alb, unplanned wt loss

Lots of us have it-- so what's the BIG DEAL??

Backflow of partially digested food and acid



Pain and inflammation and ulceration



GI bleed/esophageal cancer/aspiration of stomach contents



Death

GERD is dangerous over **TIME**

can also contribute to risk for **ASPIRATION**

Diagnosis: symptom report and improvement

ID/DD: PH monitor, barium swallow, endoscopy,
oxygen saturation

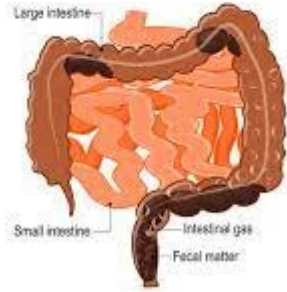
TX: medications, positioning at meals and at night



THINK ABOUT IT TO RECOGNIZE IT!



Constipation



Constipation

(KON-stih-PAY-shun) **A condition in which stool becomes hard, dry, and difficult to pass, and bowel movements don't happen very often.** Other symptoms may include painful bowel movements, and feeling bloated, uncomfortable, and sluggish.

Risk factors for constipation

- Dehydration
- Not enough dietary fiber
- Lack of muscle function/tone
- Nerve problems or damage
- Inactivity/immobility
- Certain medications, including iron and calcium supplements
- Surgery or hospitalization
- Being female
- Being elderly



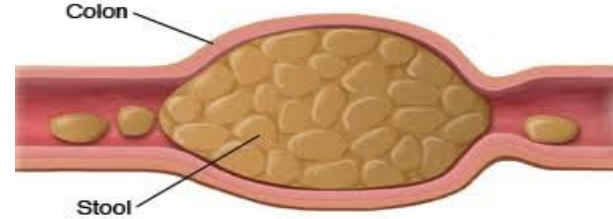
Constipation causes:

Cause of everything:

Fever, anorexia, vomiting, seizures, medication intoxication, decreased LOC, pneumonia, behavioral outbursts, death

Causes:

Decreased gi motility, immobility, lack of sensation, diet, medications (anti-epileptic drugs, antipsychotics, iron, anticholinergics, opiates), pica



How to **help** with constipation

1. Encourage a well-balanced **diet**

2. Integrate physical **activity** into the day

3. Try **probiotics**

4. Be aware of **sodium**

5. Increase **fluid** intake

6. Discourage **alcohol** consumption.

7. **Track** bowel movements

8. Support regular **bowel habits**

9. Consider stool **softeners**



Constipation treatment- Meds

Diet supplements: fiber, adequate fluids, pro-biotics

Laxatives- MOM, mag citrate, PEG

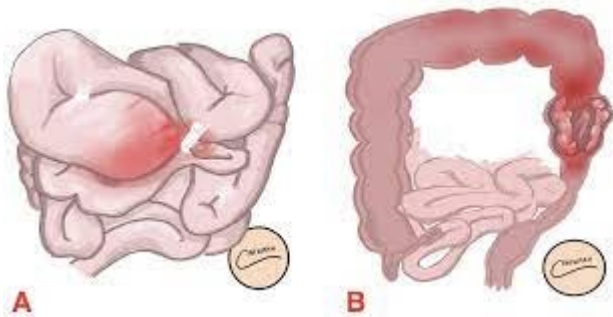
Suppositories

Enemnas

Manual disimpaction







PLUS: Bowel Obstruction

(BOW-ul ub-STRUK-shun) **A partial or complete block of the small or large intestine that keeps food, liquid, gas, and stool from moving through the intestines in a normal way.**

Bowel Obstruction

Highest community based cause of preventable death

Repeat occurrences are the highest risk

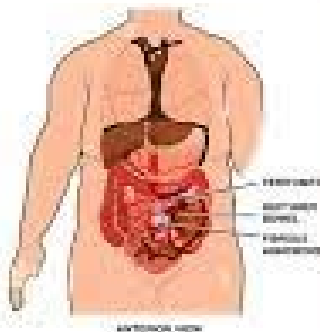
Causes: Multiple drugs, constipation side effects, dietary habits (low fiber and fluids) and ironically, meds intended to improve elimination can place the individual at higher risk for impaired bowel function.



Back-up
bowel contents

Blockage of large
intestine caused by
diverticulum

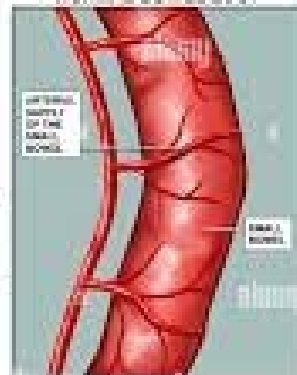
Anterior cut-away view



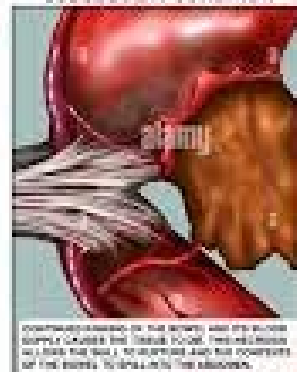
ANTERIOR VIEW

Peristalsis

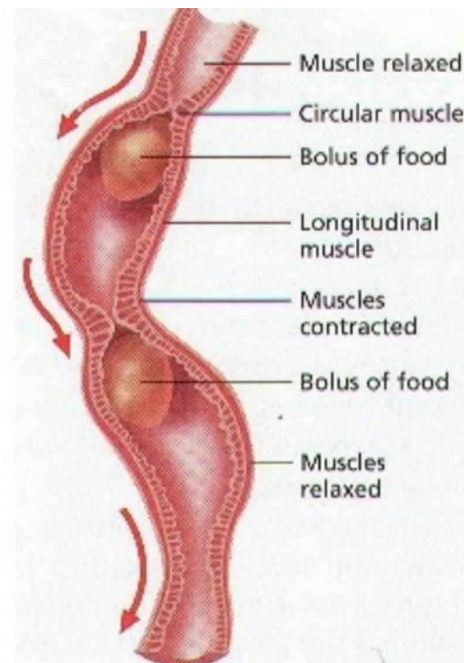
NORMAL BOWEL LOOP



SUBSEQUENT CONDITION



INITIAL CONDITION



Bowel Obstruction

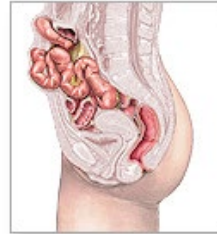
Change in diet, change in settings/activities, inability to communicate pain accurately, over-reliance on bowel meds

Blocking of movement through the GI tract from scar tissue, lack of movement (peristalsis) or constipation or foreign body

Ask: what is normal, what pattern do staff/family see

Think of it and you will not miss it

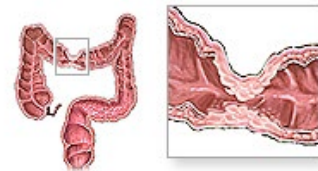
Umbilical hernia

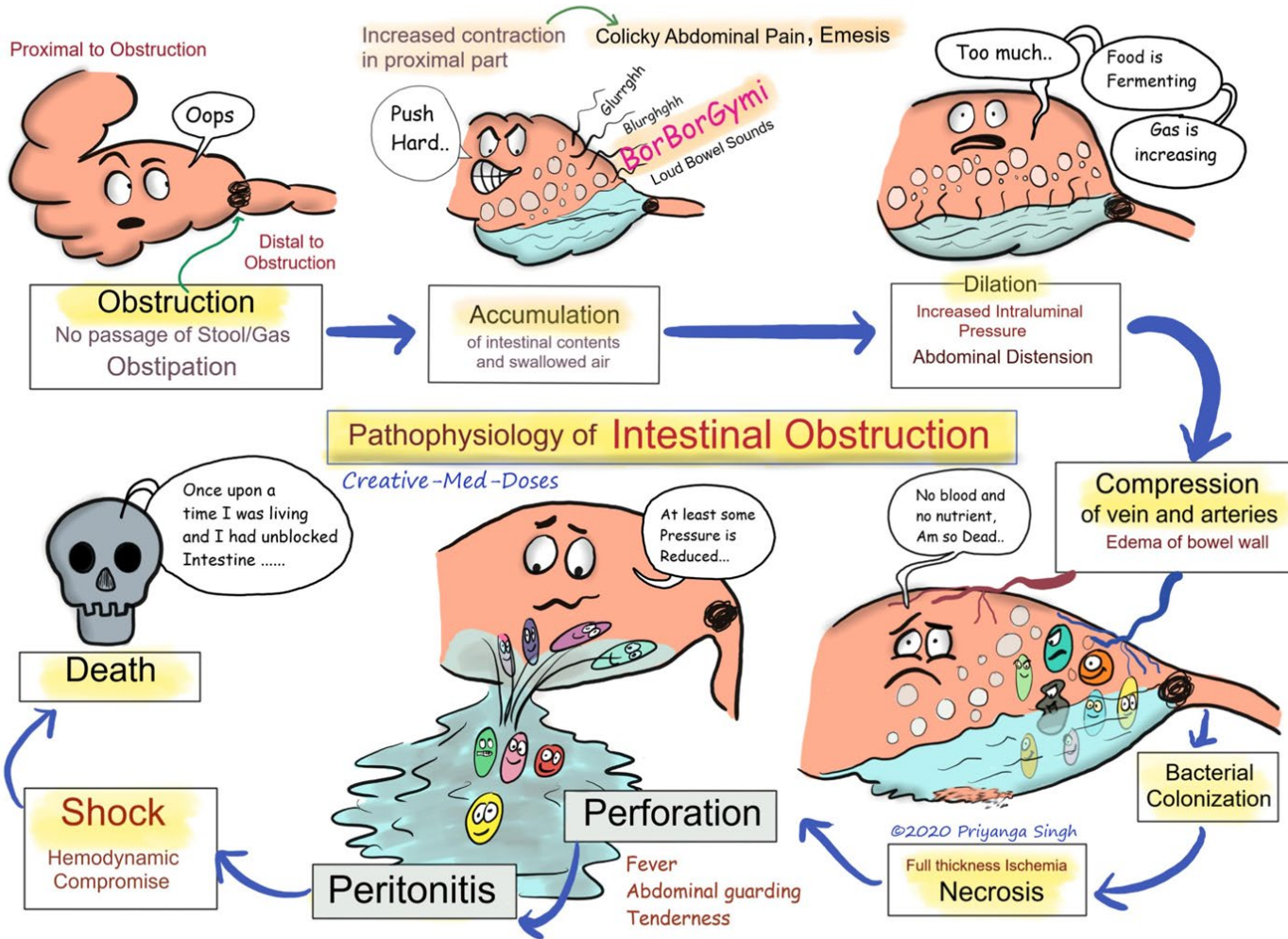


Adhesions



Colon cancer









Dehydration

A condition that occurs when the body loses too much water and other fluids that it needs to work normally. Dehydration is usually caused by severe diarrhea and vomiting, but it may also be caused by not drinking enough water or other fluids, sweating too much, fever, urinating too much, or taking certain medicines.

Dehydration

How much water is best?



13 c for men and 9 cups for women. “Avg healthy adult, temperate climate”

8 by 8

If you feel thirsty, you are already dehydrated

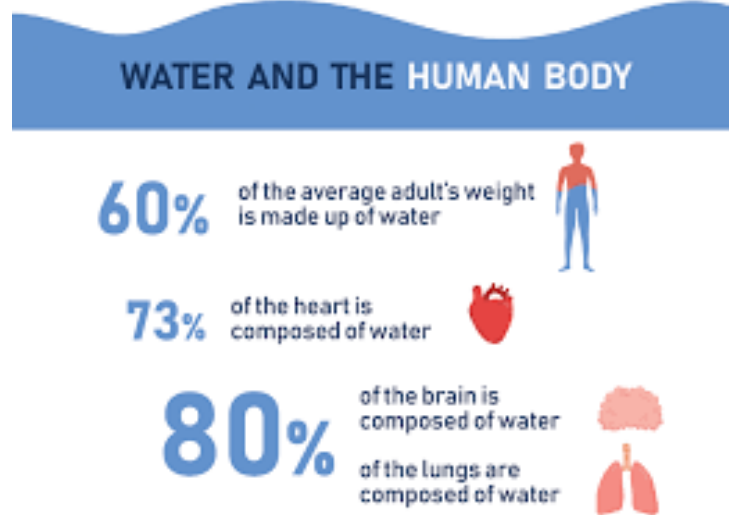
EX: Extra for exercise/exertion/excretion/ex-well



Why Water?

About 60% of your **body weight** is made of **water**. You need it for every single body function. It flushes toxins from your organs, carries nutrients to your cells, cushions your joints, and helps you digest the food you eat.

If you don't get enough **water**, you can become dehydrated. Severe cases of **dehydration** can cause **dizziness**, confusion, and even **seizures**.



What Counts as 'Water'?

Your recommended water intake includes all sources -- drinking water, other beverages, and food. But be careful -- certain fluids have their drawbacks.

Juices, sodas, and **smoothies** --high in **sugar** and calories

Coffee and **tea** --contain **caffeine**

Alcoholic drinks -- cause you to lose more water through your **urine**

Sports drinks--contain carbohydrates and **electrolytes**, but be careful: many also contain lots of extra calories, **sugar**, and salt.

Energy drinks --contain sugar, as well as stimulants, like **caffeine** -- often in high doses.

And don't forget foods! **Fruits and vegetables** like cucumbers, iceberg lettuce, celery, and watermelon are over 90% water. They also provide a variety of different **vitamins** and minerals.

Refreshing!



Flavored waters and making water fun makes it easier for many people to add-- or switch from a less desirable fluid!!



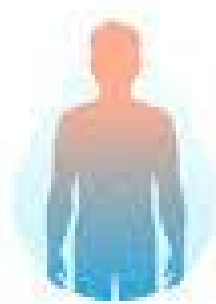
Risk factors for dehydration



- Vomiting and diarrhea increase fluid loss.
- Illness, including fever, infections, or other common illnesses, can increase the body's need for fluid while also decreasing the person's motivation to drink.
- Diabetes can increase fluid output.
- Decreased fluid intake for any reason is a concern.
- Excessive exertion or perspiration can increase fluid loss.
- Extreme temperatures – both hot and cold – can cause fluid loss.
- Advanced age reduces a person's ability to retain water.
- Certain medications increase fluid loss through urination.
- Infants and small children lose fluid more easily than adults do

Dehydration

Those who don't swallow well are especially likely to refuse fluids or indicate fear when they get them, often resulting in dehydration. We may try to restrict fluids to prevent incontinence, not realizing the lack of fluids can contribute to constipation and increased seizure frequency, not to mention drug toxicity and other health problems. Summer, illness, and extra body movements increase risk.



Thirst



Headache

DEHYDRATION SYMPTOMS



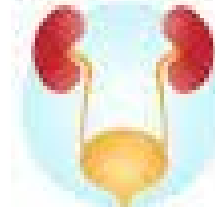
Dry Mouth



Rapid Heartbeat



Dry Skin



Decreased Urination

Signs of dehydration

- Feeling thirsty
- Dry mouth, tongue or skin
- Muscle cramps
- Feeling “low energy”
- Constipation
- Headache
- Tiredness or lethargy
- Irritability
- Decreased urine output or dark, concentrated urine
- Dizziness or fainting
- Rapid heartbeat or breathing
- Confusion or disorientation





Dehydration



Vomiting

Limited intake

Limited ability to communicate thirst, immobility to access fluids, loss during intake, medical conditions (DM) , staff awareness

Dysphagia

Drooling

If PEG tube-- adequate amount of fluids provided

Draining PEG-- excess fluid loss, without replacement-- follow electrolytes

What to do about dehydration



Help the people you support **build routines**

Have a glass of water after coming home from work or school.

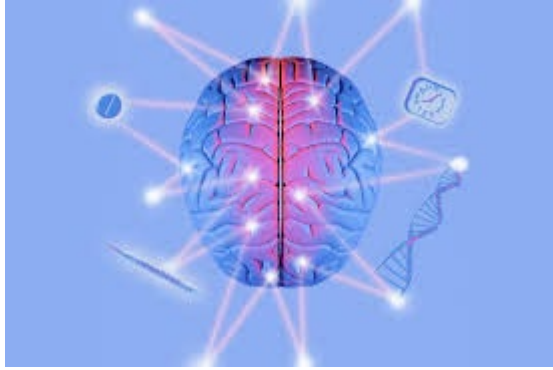
When you finish one activity, offer a drink before starting the next.

Carry a large water bottle with them throughout the day

When you take a drink, offer those you care for one, as well

Habits like this can make staying hydrated almost second nature.





FOCAL
SEIZURE



GENERALIZED
SEIZURE

Seizures

A seizure is a burst of uncontrolled electrical activity between brain cells (also called neurons or nerve cells) that causes temporary abnormalities in muscle tone or movements (stiffness, twitching or limpness), behaviors, sensations or states of awareness.

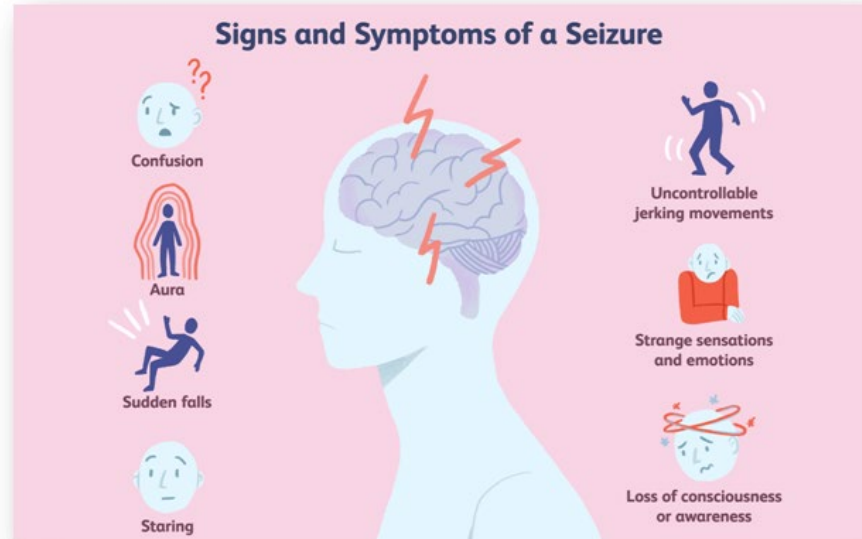
Seizures

New onset vs known

Drug toxicity: AED are always one of the top 10 most dangerous drugs

Risk factors for seizures;

- Stroke
- Brain injury
- Dementia
- Brain infections
- Liver or kidney failure
- Severe high blood pressure
- High fever (typically in children)
- Drug use or toxic substances



Stroke

Precipitating factors-seizures

Constipation

Infection

Med compliance

Hypoglycemia

Electrolyte Imbalance

Shunt Issues (LOC)

Head Injury

Menses



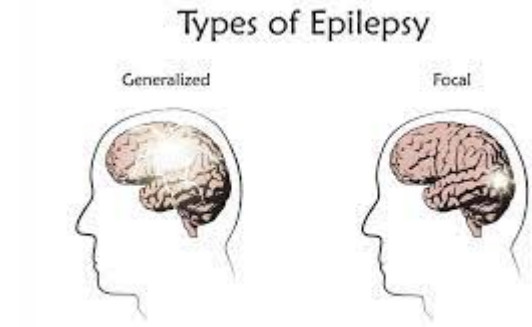
Seizures

An alteration in brain function resulting in changes in awareness, or function for a brief period of time

A seizure is a sudden, uncontrolled electrical disturbance in the brain. It can cause changes in your behavior, movements or feelings, and in levels of consciousness.

Having two or more seizures at least 24 hours apart that aren't brought on by an identifiable cause is generally considered to be epilepsy

REM: rapid eye movement, sub-clinical



Seizure Sequelae

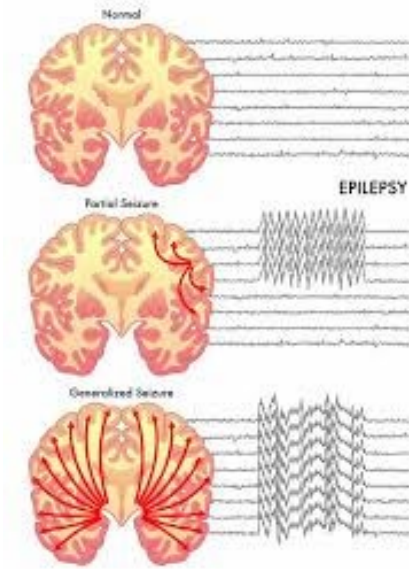
Aspiration

Respiratory suppression

Trauma/Accidents

Uncontrolled/Status

Death
drug toxicity, SUDEP



25% have epilepsy dx, 70% of those continue to experience seizures, despite meds.

Life expectancy for persons with active seizure d/o has shown to be up to 10 years less than those without the condition.

Seizures, what to do

Ease the person to the floor or help to lay back

Turn the person gently to one side (helps breathing)

Clear the area round the person (no sharp or hard)

Put something soft under the head

Remove eyeglasses

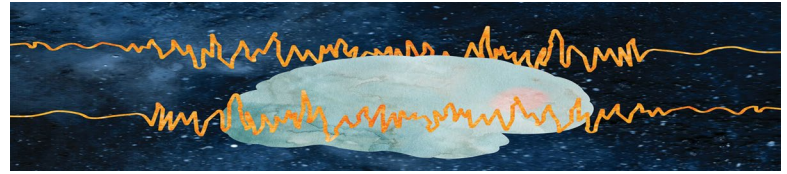
Loosen ties/neck

Time the seizure, call if >5 min or according to protocol

Offer meds +/-



How to help with seizures



- **Monitor for environmental risks.** Falls, furniture, hazards
- **Prevent choking or aspiration.** Increased risk for vomiting, aspiration
- **Do not restrain them.**
- **Prepare to report.** Details will help determine potential cause or preventable future events
- **Support the aftermath.** Disoriented, frightened, tired, or weak. Stay with them until you are sure they are fully awake.
- **Get help if you need it.** Call 911 if indicated on the person's plan, if any concerns about the course of their seizure, anyone who is not breathing, who is pregnant, who sustains a significant injury due to a fall or other hazard, or who has never had a seizure

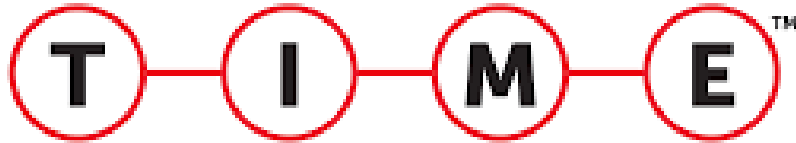
Ways to prevent seizures and related injuries

1. Provide medication support
2. Avoid known seizure triggers
3. Know their warning signs
4. Recommend showers
5. Beware the heat
6. Support sleep hygiene
7. Treat fevers
8. Help manage stress
9. Recognize situational hazards
10. Document all seizures





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



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?"

©2020 Sepsis Alliance

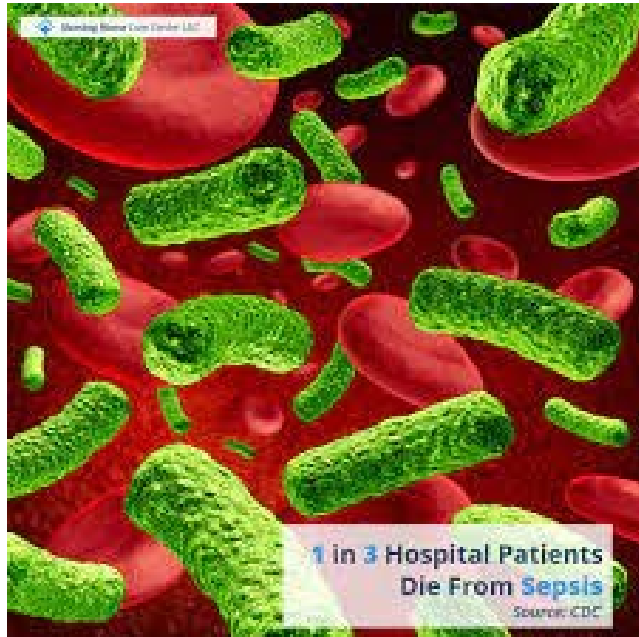
sepsis.org



Plus: Sepsis

Blood poisoning due to failure of the immune system
to respond to infection






Sepsis is a **potentially life-threatening condition** that occurs when the **body's response to an infection damages its own tissues**. When the infection-fighting processes turn on the body, they cause organs to function poorly and abnormally. Sepsis may progress to septic shock.



DO YOU KNOW THE

SIGNS OF SEPSIS?

Sepsis kills 270,000 Americans annually and is a medical emergency.

					
FEVER/ SHIVERING OR VERY COLD	RAPID BREATHING	EXTREME PAIN/ PHYSICAL DISCOMFORT	PALE OR MOTTLED SKIN	DISORIENTED/ CONFUSED & SLEEPY/ DIFFICULT TO WAKE	ELEVATED HEART RATE

endsepsis.org

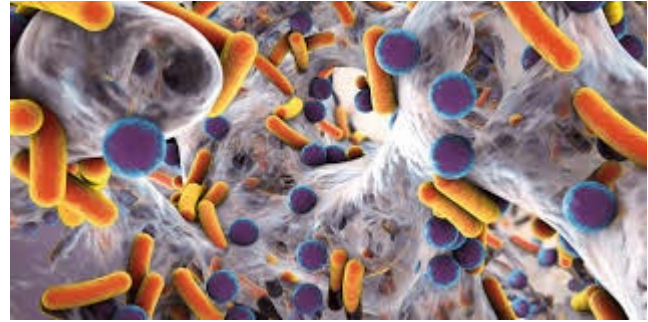
ENDSEPSIS

Sepsis



Infection often comes from : burns, ulcer, open wound, pneumonia, uti

Signs and symptoms: high temp, rapid pulse, chills, low blood pressure, mottling of the skin, confusion and lightheadedness



**Every hour raises risk by
10%**

Treat aggressively, high hospital mortality rate

In summary:

Fatal Five:

Aspiration

Constipation

GERD

Dehydration

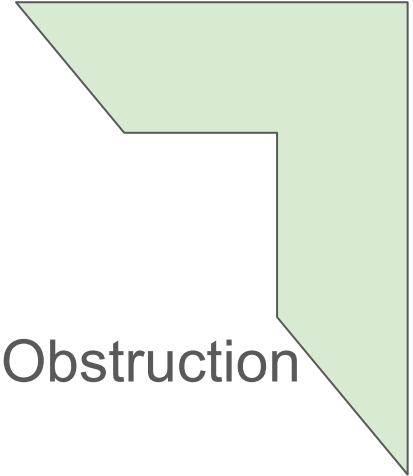
Seizures

PLUS:

Bowel Obstruction

Sepsis

But wait... there's more...



Other Vulnerable Populations

Dementia

Chronically Ill

Very Old

Low Income and Homeless

Substance Use



Possible Connections

Seizures

Constipation GERD Aspiration

Dementia

X

X

X

X

X

Chronically Ill

X

X

X

X

X

Elderly

X

X





Intellectual /developmental disability is never a root cause of death

Cerebral palsy does NOT cause constipation,
lack of movement does

Cerebral palsy does NOT cause aspiration,
Change in body structure due to abnormal movement does



***Most important part of fixing a problem
is figuring out what the problem IS***

Assess



Is the condition/ concern getting Better or Worse

Do not let chronic health issues become routine or invisible

Records must provide useful data about treatments

Monitor residential settings to assure health and safety

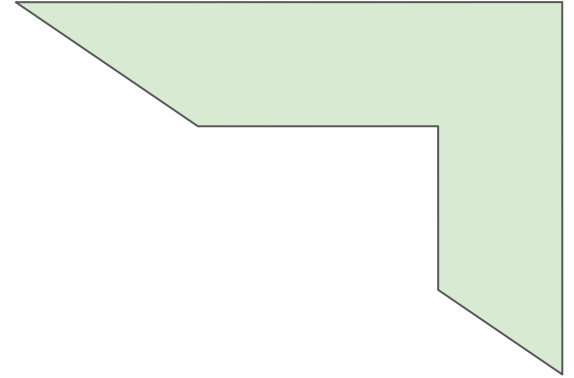
Don't discount reports by parents/staff

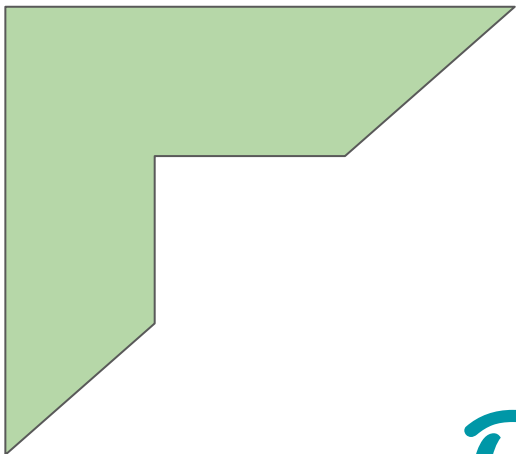
and find solutions

Recognize the signs of trouble

Develop and early warning system to detect destabilization

When in doubt, reach out





Be an ambassador



Be aware



DRINK LOTS OF WATER!



QUESTIONS?

~Be Curious~





THANK YOU!

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 **Bluestone**
*Physician Services*SM