The Fatal Five in IDD ASPIRATION

Inhaling particles into the airway; food or drinks "going down the wrong pipe"

WARNING SIGNS

- Drooling during meals
- Changes in breathing patterns
- Regular coughing or sneezing while eating
- Making gurgling sounds after eating
- Shortness of breath
- Excessive throat clearing
- Feeling like something is stuck in their throat
- Sudden coughing, wheezing, or hoarseness

RISK FACTORS

- Difficulty swallowing (dysphagia)
- Eating too quickly
- Putting too much food in their mouth
- Difficulty controlling head or neck muscles
- Difficulty sitting up straight
- Not fully conscious or aware
- Dental problems that prevent adequate chewing
- A small airway, a large tongue, or other anatomical variation
- Gastroesophageal Reflux Disease (GERD)

WHAT TO DO

- Encourage them to spit out any food or beverage.
- Encourage them to keep coughing to clear the material from their airway.
- Do not give them more food or drink until they have returned to their baseline.

SIGNS OF ASPIRATION PNEUMONIA

Cough, especially involving bloody or green sputum

Shortness of breath or wheezing

Chest pain or painful breathing

Fever, perspiration, and fatigue

Swallowing difficulty, not pre-existing

Blue tinge to the face or lips

Bad breath not from dental issues



The Fatal Five in IDD CONSTIPATION

RISK FACTORS

- Dehydration
- Nerve problems or damage
- Not enough dietary fiber
- Inactivity/immobility
- Surgery or hospitalization
- Poor muscle function or tone
- Iron and calcium supplements
- Being female, especially if pregnant
- Diabetes, Crohn's disease, multiple sclerosis, or irritable bowel syndrome

WHAT TO WATCH FOR

- Abdominal bloating or pain
- Straining on the toilet
- Feeling like they still need to go after having used the bathroom
- Infrequent stools
- Hard or lumpy stools
- Gas or liquid stool

HOW TO PREVENT CONSTIPATION

Encourage a balanced, healthy diet

Increasing fiber and reducing dairy or red meat can ease or prevent constipation.

Increase intake of fluids

Constipation occurs when stools are dry, so increasing fluids can help.

Support and develop routines

Routines such as using the toilet at a certain time of day promote healthy bowel habits. Plan ahead. Unless absolutely necessary, never advise someone to "hold it."

Increase physical activity

Integrating physical activity into the day helps get the digestive tract moving.

Discourage alcohol consumption

Alcohol consumption increases dehydration and constipation.

Try probiotics

Some studies have shown that probiotics, like the kinds commonly found in some varieties of yogurt, can improve many bowel problems, including constipation.

Be aware of sodium intake

Salt dries out the stool and increases the risk of constipation.

Record bowel movements

Tracking frequency, size, and consistency will enable you to identify and intervene.

Consider stool softeners

Many people with IDD benefit from regular use of stool softeners or fiber supplements to make their stools easier to pass. Note that although many of these are available over the counter, in many service settings you will need a physician's order to use them.



The Fatal Five in IDD DEHYDRATION

RISK FACTORS

- Extreme temperatures, both hot and cold
- Diabetes
- Decreased fluid intake for any reason
- · Vomiting and diarrhea
- Being elderly or very young
- Common illnesses, fever, and infections
- Excessive exertion or perspiration
- Medications that increase urination

WHAT TO WATCH FOR

- Feeling thirsty
- Decreased urine output or dark, concentrated urine
- Tiredness or lethargy
- Muscle cramps

- Low energy
- Dizziness or fainting
- Irritability
- Headache
- Constipation

- Confusion or disorientation
- Dry mouth, tongue, or skin
- Rapid heartbeat or breathing

HOW TO PREVENT DEHYDRATION

Build regular and healthy routines

Help the people you support build routines, such as having a glass of water after coming home from work or school or when an activity is finished.

Beware alcohol and salt

Both impact the body's electrolyte balance. A diet high in salt or drinking any amount of alcohol requires increased fluid consumption.

Monitor and track fluid intake

If you are working with someone who can't manage their own fluid intake, be sure to keep good records to coordinate with other staff.

Be a role model for them

Offer frequent reminders to drink fluids. If you are thirsty, suggest that you and the person you support get a drink together.

Be creative with your support

Figure out how the individual prefers their liquids. Carbonated?
Fruit flavored?
With a straw?

Know what counts and hydrates

Almost any fluid provides hydration, including coffee, tea, soda, some fruits and vegetables, popsicles, smoothies, and similar treats.

Consider consistency of liquids

Some people may have trouble swallowing thin liquids and may prefer thicker beverages, such as smoothies.



The Fatal Five in IDD SEIZURES

WARNING SIGNS

- Drooling
- Vomiting
- Sensory abnormalities
- Tremors or "shaking"
- Unusual eye movements
- Exhaustion
- Headaches
- Incontinence
- A scream or cry
- Loss of consciousness
- Disorientation or confusion
- Appearing "absent" or staring
- Loss of control over parts of the body

HOW TO HELP DURING SEIZURES

- Help the person prevent injury from colliding with furniture or other things
- Prevent choking by putting them on their side or in recovery position
- Do not restrain them

- · Get help if needed
- Follow the personalized seizure plan
- Report what happened before and during seizure to medical team
- Help the person deal with fear or disorientation after seizure
- Do not offer food and drinks until they have recovered
- Stay with them until fully awake

HOW TO PREVENT SEIZURES

Recommend showers
It takes very little water
to drown, so a seizure
while in the bath can be
fatal. Encourage a person
at risk for seizures to take
showers instead.
The use of a shower chair
can reduce the risk of
slipping and falling if
a seizure occurs.

other illnesses
Illnesses, particularly high
fevers, can sometimes
trigger seizures, particularly
in individuals with a

Treat fever and

Beware heat and dehydration Intense heat can increase dehydration, which increases the risk of seizures.

known seizure disorder.

Recognize situational hazards

A person with a seizure disorder can often take part in a wide variety of typical activities. You need to be aware of which activities pose a special risk for the person you support. Stairs, for example, can be dangerous for someone who typically falls when they seize and who has no prior warning of an oncoming seizure.

Know their warning signs
Some people have specific
warning signs prior to a seizure.
The person may feel dizzy, lose
sensation in part of their body,
or have other specific signs
that a seizure is about to happen.
Recognizing these signs can
create an opportunity to
lie down, move away from
hazards, or call for help
if needed.

Document all seizures
High levels of stress can
trigger seizures as well as

trigger seizures as well as other risk factors, such as not getting enough sleep.

Avoid known triggers
Triggers vary and may
include specific songs,
flashing lights, hormonal
fluctuations, or drug
or alcohol use.

Help manage stress levels

High levels of stress can trigger seizures as well as other risk factors, such as not getting enough sleep. Provide
medication support
Help the individuals
you serve take
their anticonvulsant
medications on time
and as prescribed
by their doctor.

sleep hygiene
Good sleep hygiene
includes going to sleep
and waking up at the
same time every day
and avoiding caffeine
and blue screens late

Support

at night.

RELIAS relias.com

The Fatal Five in IDD SEPSIS

Extreme response to an infection which triggers a chain reaction throughout the body and can quickly lead to tissue damage, organ failure, and death if left untreated.

RISK FACTORS

- Age, specifically people over 65 and children younger than 1 year old
- Compromised immune systems
- Chronic health conditions such as diabetes, lung disease, cancer, and kidney disease
- People who have had sepsis in the past
- Pregnant women
- People who have poor hygiene or live in an unhealthy environment

WHAT TO WATCH FOR

- Fast heart rate or low blood pressure
- Fever, shivering, or feeling cold
- Confusion or disorientation
- Difficulty breathing
- Severe pain or discomfort
- Skin that feels sweaty or clammy

HOW TO PREVENT SEPSIS

Contact medical professionals

In case of emergency, contact the nurse or the person's physician and let them know the symptoms you have seen and share your concerns.

Prioritize hygiene

Encourage good personal hygiene, including handwashing.

Take care of any injuries

Keep cuts and wounds clean and covered until healed, unless otherwise directed.

Know the signs

Know the signs and symptoms of sepsis.

Manage other conditions

Help the person manage chronic health conditions, such as diabetes, osteopenia, and dementia.

Understand your client

Know the health history of the person you serve.



Dysphagia: Risks, Signs, & Choking Prevention

\$\ \text{What Is Dysphagia?}

Dysphagia is the medical term for **difficulty swallowing**. It can affect any part of the swallowing process—from the mouth to the esophagus—and may result in choking or aspiration.

Dysphagia can develop at any time and is often linked to underlying medical or physical conditions. It can cause choking and aspiration, both of which may lead to injury, illness, or death.

Who Is at Risk?

Individuals at higher risk include those with:

- Intellectual or developmental disabilities (IDD)
- Neurological conditions (e.g., stroke, cerebral palsy, Parkinson's, ALS)
- Dementia or traumatic brain injury
- Poor oral health (e.g., missing teeth, ill-fitting dentures)
- GERD (acid reflux)
- · Feeding tubes or tracheostomies
- Use of certain medications that affect muscle tone or alertness

∴ Symptoms of Dysphagia

- Coughing or choking while eating
- Excessive drooling
- Frequent throat clearing
- Complaints like "food is getting stuck" or "going down the wrong pipe"

- Eating too fast or packing food in the mouth
- Difficulty breathing during or after meals

Choking is when food or objects block the airway, preventing oxygen from reaching the lungs. This can quickly lead to **brain damage or death**.

Signs of Choking

- Red or gray/blue skin
- Hands at throat
- Noisy or labored breathing

- Inability to speak or cough
- Loss of consciousness

Immediate Action

- Call 911!
- If conscious and unable to breathe, **perform abdominal thrusts**.
- If unconscious, call 911 and begin CPR.

Heimlich Maneuver (Abdominal Thrusts)

- 1. Stand behind the person.
- 2. Place your arms around their waist.
- 3. Make a fist and place thumb side above the navel.
- 4. Grasp the fist with your other hand.
- 5. Perform quick, upward thrusts until the object is expelled.

Impact on Individuals with Intellectual Disabilities

- May not communicate discomfort clearly.
- Behavioral changes (e.g., food refusal, agitation) may signal swallowing issues.
- Require close supervision during meals.
- Need individualized care plans with:
 - Prescribed food textures
 - Positioning instructions

 Adaptive equipment (e.g., specialized cups, utensils.

Prescribed Diets

Based on swallowing assessments, individuals may be prescribed:

- Modified food textures: pureed, minced, soft, chopped in certain size
- Thickened liquids: mildly to extremely thick
- Avoidance of high-risk foods: dry, crumbly, sticky, stringy, or tough items

Treatment & Prevention

- Swallowing studies (e.g., videofluoroscopy)
- **Speech therapy** for swallowing techniques
- Adaptive equipment for safe eating
- Oral hygiene and proper denture fit
- Staff training on care plans, prescribed diets, and emergency response

Additional information on dysphagia and choking prevention can be found at the link below from Office of Developmental Programs Announcement 25-070 Update 8/14/2025

https://www.pa.gov/agencies/dhs/resources/choking-prevention

Prescribed Diet Training Overview

1. Purpose of Prescribed Diets

Prescribed diets are medically recommended eating plans tailored to:

- Manage chronic conditions (e.g., diabetes, heart disease, celiac)
- Support allergies or intolerances (e.g., gluten-free, lactose-free)
- Promote overall health and wellness
- Align with behavioral or sensory needs

2. Key Training Objectives

Staff and caregivers should be trained to:

- Understand the diet plan: Know what foods are allowed, restricted, and why.
- Follow instructions accurately: Prepare and serve meals according to the plan.
- Monitor and document: Track food intake, reactions, and compliance.
- **Communicate effectively**: Share updates with families, dietitians, and healthcare providers.
- Respect individual preferences: Balance medical needs with cultural and personal choices.

3. Common Types of Prescribed Diets

- Low-sodium: For heart health and blood pressure control
- Diabetic-friendly: Low sugar, balanced carbs
- Gluten-free: For celiac disease or gluten sensitivity
- Texture-modified: Pureed or soft foods for swallowing difficulties
- Allergen-free: Avoiding nuts, dairy, eggs, etc.
- **High-fiber or low-fiber**: Based on digestive needs

4. Person-Centered Approach

In line with **Everyday Lives** values:

- Choice and Control: Individuals should be involved in meal planning when possible.
- **Communication**: Use preferred methods to explain food options and gather feedback.
- Respect and Dignity: Honor cultural, religious, and personal food preferences.
- Health and Safety: Ensure food safety and proper nutrition while respecting autonomy.

5. Documentation and Compliance

- Record meals served and eaten
- Note any refusals, substitutions, or reactions
- Communicate with healthcare providers about concerns
- Ensure compliance with licensing and regulatory standards

6. Texture Modification References



Regular Diet

Whole foods



Soft & Chopped

- Avoid dense, stringy foods
- Cut into quarter or dime sized bites



Moist & Minced

- Blended in a food processor with a small amount of liquid added.
- Retains some texture, but fine



Pureed

Blended until smooth

Prescribed Diet Consistencies/Textures (complete and attach this form to annual physical and any swallowing evaluation completed by a speech pathologist) CLIENT NAME: HOUSE/PROGRAM: RHD Lifesharing **CALORIE COUNT PER DAY:** ____1500 ______1800 ______2000 ______Other, please indicate: 1200 **DIET:** (check one) NPO (nothing by mouth) _____ House ____ ADA American Diabetes Association Recreational Feedings Only (g-tube diet but may also have pleasure feed by mouth) CHECK ANY THAT ALSO APPLY: Low Cholesterol Low Triglycerides Low Salt Low Fat High Fiber ____ Other, please list: **FOOD CONSISTENCIES** (check one from this column): Regular Diet- individual is able to cut their own food, no choking or aspiration risks Assisted Regular Diet- individual needs assistance to cut food, no choking or aspiration risks Quarter-Size Regular Diet- staff must cut food prior to serving due to individual's inability to cut food, food less than one inch in diameter, no choking or aspiration risks Dime-Size Regular Diet- staff must cut food prior to serving due to individual's inability to cut food. Cut to 1/2-3/4 inch in diameter. Quarter-Sized Soft Diet- food is of soft/moist consistency, requiring some chewing, less than one inch in diameter, may add liquid to moisten Dime-Sized Soft Diet- food is of soft/moist consistency, requiring some chewing, and cut to 1/2-3/4 inch in diameter, may add liquid to moisten Mechanically Chopped Soft Diet-food processor is used, check to ensure no large chunks, moist consistency, chopped to less than 1/2 inch in diameter (smaller than a raisin), and may add liquid to moisten Fine/Ground Soft Diet- food processor used longer, crumbly/moist consistency, ground to less than 1/4-1/8 inch (size of piece of rice or smaller), ensure no chunks, and will likely add liquid to moisten Pureed, Pudding-Like Diet- food processor used, smooth, pudding-like, very moist consistency, ensure no chunks, strainer can be used, likely need to add liquid to moisten **LIQUID CONSISTENCIES** (check one from column): FLUID RESTRICTIONS: yes Thin/Regular Consistency if yes, ccs/24 hours ____ Nectar-Like Consistency ASPIRATION PRECAUTIONS: yes please note any specific instructions ___ Honey-Like Consistency Spoon-Thick/Pudding-Like Consistency FOOD ALLERGIES: please list PCP or Speech Pathologist/ Name Signature Date

1

Eating, Drinking, Swallowing Checklist

Individua	's Name:	Date of Completion:								
Form Co	mpleted By:	Title:								
		on gathered about the eating, drinking and swallowing ions 1 and 2; Have physician complete Section 3.								
Living arr	angement (i.e., home, residential living, shar	ed living, etc):								
Type of s	etting where form is completed (i.e., home, d	lay program, employment site, etc):								
	I: Circle Yes or No For Each Item ng Eating & Drinking Habits:									
Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No	Steals food Hides food Generally grabs food Takes in too much food and or liquid at one a breath or unable to limit bite/sip size) * Eats while moving around environment Eats with a tablespoon Excessive length of time to complete meal									
Risky Sw	allowing & Eating Concerns									
Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No	Loss of food or drink out of mouth during of Holding or pocketing food/liquids * Swallow foods whole * Inadequate chewing * Repeated attempts to swallow * Watery eyes/nose during or after eating Difficulty swallowing medication (i.e., unab gags, spits out, pocket/hold pills in mouth) Poor positioning risk factor (tilts head back drinking)	le to swallow large or multiple pills								
Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No	Episodes of coughing/choking during or aff Wet/gurgly voice during or after meals (if p "ah" or vocalizing) * Increased congestion/secretions following r Excessive throat clearing * Increased temperature of an unknown cause Frequent upper respiratory infections/pneur	ossible listen to the person say meals * se (temperature spikes) *								
Yes/ No Yes/ No Yes/ No Yes/ No Yes/ No		llowing ** 3 **								
	or validitororiiiiolito.									

Section 2: Answer Each Item

ISP instructions surrounding eating and/or drinking, if any:
Current diet/food prep/liquid level consistency, if any:
Dentition (i.e., edentulous (has no teeth), dentures, etc):
Oral hygiene routineindependent? dependent? with assistance?
Type of oral hygiene products used? (i.e., paste, mouth wash, toothbrush, swab, etc):
Any aspiration precautions/guidelines? Yes/ No
Any adaptive feeding equipment used? Yes/ No if yes, what type(s)?
Current or past diagnosis of dysphagia? Yes/ No
Current or past diagnosis of GERD? Yes/ No
Other medical/psychiatric diagnoses: (list all)
Current medications, list all including "over-the-counter": (attach list if necessary)
Section 3: To be Completed by Physician
Dear Physician, please review both sides to assess if additional supports or evaluations are needed with regard to eating, drinking, swallowing. Thank you.
Physician reviewing form: Physician Signature: Date:
Follow up instructions from physician, if any:

Lifesharing Meal Observation Log

Instructions:

- 1. Use at all eating/drinking times with participants who have been ordered special instructions around eating/drinking.
- 2. Complete all information at top of form.
- 3. Initial that instructions for the participant are being followed as applicable per ISP/MD orders.
- 4. Report non-life threatening concerns immediately by telephone to the Program Specialist, AD or UD. Use back of form to detail concerns and follow up.
- 5. Submit completed form each week to Unit Director or designee.
- 6. Unit Director or Designee: Review weekly. Complete follow up. Sign and date. Upload to program folder in Teams.
- 7. In the event of choking, difficulty breathing, any life threatening concern, DIAL 911.

Individual:																						Aut	ui es	5.										VV	/eek	. 01.	_					
ISP Meal/Eating In	stru	uctio	ns:																																							
Diet:																																										
	_						1												1						ır												_					
		Sunday					Monday				Tuesday				Wednesday				Thursday					Friday					Saturday													
Enter N/A if any of the items below do not apply. Use 'Other' box to enter additional instructions.	Breakfast	Lunch	Dinner	Snack #1	Snack #2	Snack #3	Breakfast	Lunch	Dinner	Snack #1	Snack #2	Snack #3	Breakfast	Lunch	Dinner	Snack #1	Snack #2	Snack #3	Breakfast	Lunch	Dinner	Snack #1	Snack #2	Snack #3	Breakfast	Lunch	Dinner	Snack #1	Snack #2	Snack #3	Breakfast	Lunch	Dinner	Snack #1	Snack #2	Snack #3	Breakfast	Lunch	Dinner	Snack #1	Snack #2	Snack #3
Food prep followed (cutting/blending/thickener):																																										
Adaptive equipment working and used;																																										
Seating/positioning followed:																																										
Observation and/or Prompting:																																										

Provider Initials	Provider Printed Name	Provider Signature	Provider Initials	Provider Printed Name	Provider Signature

See reverse for reporting and signatures

Comments/Concerns

Describe all concerns, including what the concern was, who the concern was reported to, the time reported, and resolution.

Date:	Time:	Concern:		Reported to:
Date/Time i	reported:		Resolution:	
Provider Re	porting Concer	n:		
Date:	Time:	Concern:		Reported to:
Date/Time i	reported:		Resolution:	
			7	
Provider Re	porting Concer	n:		
Date:	Time:	Concern:		Reported to:
Date/Time i	reported:		Resolution:	
Provider Re	porting Concer	n:		
Date:	Time:	Concern:		Reported to:
Date/Time i	reported:		Resolution:	
Provider Re	porting Concer	n:		
Date:	Time:	Concern:		Reported to:
Date/Time i	reported:		Resolution:	
		_	·	
Provider Re	porting Concer	n:		
<u> </u>				
Weekly Revie	ew Completed	Ву:		
Date:				
Date Upload	ed to Teams:			

Symptoms: Recognize, Report, Relay to Professionals

What Is Physical Distress?

- Defined as **pain or suffering** affecting the body or mind.
- Can signal danger or urgent medical need.
- 75% of new or challenging behaviors may be linked to unmet medical needs.
- Early recognition and action can **prevent serious outcomes**.

⚠ Common Causes of Physical Distress

- Illness (e.g., infections, GI issues)
- Injury (e.g., cuts, fractures, electrocution)
- Seizures
- Medication side effects

Areas to Observe for Signs

- Head, Face, Neck: consciousness level, lip color, nasal flaring, choking
- Chest: breathing effort, respiratory rate
- Abdomen: size, softness
- Extremities: color, temperature, swelling, nail bed color
- General signs: bleeding, sweating, incontinence, behavior changes

SOS Responding to Physical Distress

- Call 911
- Provide basic first aid or CPR
- Contact the individual's physician
- Stay calm and confident

Recognizing, Reporting, and Relaying: Medical Health Concerns

- Ensure health and safety through:
 - Observation
 - Reporting
 - Documentation

© Effective Observation

- What happened **before**, **during**, and **after** the event?
- What **care** was provided?

Describing Symptoms

- **Objective**: Factual, observable (e.g., "face was red," "limping")
- Subjective: Opinions or assumptions (e.g., "looked angry," "seemed fine")
- ✓ Use objective language for clarity and accuracy.

M Avoid "Suitcase Words"

 Vague terms like "agitated" or "in pain" should be replaced with specific objective observations like "pacing while punching his palm with his fist" or "holding ankle, crying"

Reporting Essentials

- Who, what, where, when, and how keep it factual, leave out your opinion out.
- If you don't know, that's ok. **Don't jump to conclusions or adlib**.
- Include circumstances, care provided, and outcomes

Why Documentation Matters

- Supports communication with:
 - Physicians
 - Emergency responders
 - Agency & state reporting procedures
- Helps identify patterns, triggers, and effective treatments
- Prevents:
 - Misdiagnosis
 - Unnecessary tests or hospitalizations
 - Increased anxiety or behaviors

☑ Benefits of Accurate Reporting

- Better staff communication
- Efficient care
- Continuity across shifts

Recognizing, Reporting, and Relaying: Mental Health Concerns

S Clinical Complexity

Mental health symptoms may overlap with:

- Medical issues (e.g., constipation, diabetes, thyroid disorders)
- Neurological conditions (e.g., seizures, brain injury)
- Trauma (e.g., emotional, physical, sexual)
- Developmental differences (e.g., autism)

Diagnostic Principles

- Symptoms often occur in **clusters**.
- Diagnosis requires observing **changes over time**:
 - Onset
 - Frequency
 - Intensity
 - Patterns or cycles
- Severity alone is not diagnostic.
- Psychiatric disorders may present as challenging behaviors.

Role of the Mental Health Clinician

- Part of the interdisciplinary team
- Needs objective, clear information
- \bullet Limited resource—caregivers are the $\mbox{\bf eyes}$ and $\mbox{\bf ears}$ of the clinician

S Gathering Information

Include:

- Timeline of symptoms and life events
- Family and medical history
- Medication history and changes
- Baseline vs. current behavior

Reporting Symptoms

- Avoid assumptions and interpretations
- Use concrete descriptions

- Avoid "**suitcase words**" (e.g., "agitated," "withdrawn")—describe what those look like (e.g. "pacing punching his palm with his fist," or "limited eye contact, no response to prompts of a preferred activity."
- Report **best and worst** presentations of the person

✓ Conclusion

- Accurate symptom description helps clinicians make informed decisions.
- Caregivers play a vital role in tracking and communicating changes.
- Effective reporting leads to **better treatment outcomes**.