



HCQU CARES

SPECIAL EDITION

The Fatal Five: Preventable Conditions in People with
Intellectual Disability/ Autism (ID/A)



There are five health conditions that have been identified as preventable medical conditions, which may cause illness, infection, and sometimes death in people with intellectual disability/autism (ID/A). These conditions, known as the Fatal Five, are choking/aspiration, constipation, dehydration, seizures, and infection. It is important to highlight the word preventable and learn about these conditions to maintain optimal health and safety for those in your care.

Caregivers are the frontline workers, who are not only responsible for the day-to-day activities of individuals in their care, but also carry the responsibility of keeping individuals safe from unintentional medical conditions. The key to prevention is to first understand what prevention means and then create a plan to address any risk the person has for the preventable condition. The Centers for Disease Control and Prevention (CDC) defines prevention in three tiers: primary prevention, which involves intervening before health effects occur, secondary prevention, which involves screening to identify who is at risk, and tertiary prevention, which involves managing the conditions that can cause severe illness or death (CDC, n.d.).

Caregivers can identify risks associated with the Fatal Five and take steps to prevent poor outcomes from those risks by being aware of changes from baseline, reporting

observations, following care plans and Individual Service Plans (ISP), communicating with agency medical personnel, communicating with the primary care physician (PCP), and following through with updates to the person's plan of care.

Having just one of the Fatal Five conditions can cause severe illness and may lead to another Fatal Five condition if not recognized and treated. The following scenario shows how one choking episode led to an individual developing all five conditions. Choking alone can lead to severe illness or death; having all five conditions increases the risk of severe outcomes. This newsletter will provide caregivers with tips, tools, and resources to identify risks and intervene before conditions become severe, to be proactive, and to screen individuals who may be at high risk in order to manage disease processes that may lead to the Fatal Five.



The Fatal Five: Choking

Let's follow John who has a seizure disorder and experienced choking when he did not chew his food thoroughly. Reasons he did not chew his food well included loose teeth and painful teeth and gums.

Signs/Symptoms of Choking

- ❖ Red face
- ❖ Putting hands on throat
- ❖ Unable to speak or breathe
- ❖ Gagging
- ❖ Noisy or difficulty breathing
- ❖ Facial color change to blue or gray
- ❖ Loss of consciousness

(Georgia Department of Behavioral Health and Developmental Disabilities, n.d.)

Medical/Behavioral Causes of Choking

- ❖ Decayed or missing teeth
- ❖ Not wearing dentures or ill-fitting dentures
- ❖ Disorders of the brain/nervous system such as seizure disorders
- ❖ Medication side effects
- ❖ GERD-Gastroesophageal Reflux Disorder
- ❖ Low muscle tone
- ❖ Poor eating habits
- ❖ Swallowing difficulties (Dysphagia)

(Baker, 2023a)



Screening for Swallowing Difficulties (Dysphagia)

- ❖ Painful swallowing
- ❖ Inability to swallow
- ❖ Drooling
- ❖ Food coming back up
- ❖ Heartburn
- ❖ Weight loss
- ❖ Coughing/gagging while swallowing
- ❖ Sensation of food getting stuck in throat/chest

(Mayo Clinic, 2022)

Choking Prevention

- ❖ Encourage the person to sit in an upright 90 degree angle unless recommended otherwise, including those who eat meals in bed.
- ❖ Encourage sips of fluids in between bites of food.
- ❖ Give reminders to eat at a slower pace.
- ❖ Observation-Watch the person's face during snacks and meals; monitor the person chewing and swallowing to identify those at risk for choking.
- ❖ Report signs of difficulty swallowing to all caregivers and the healthcare provider.
- ❖ Document any difficulties with swallowing, and any observation of changes from the individual's baseline.





The Fatal Five: Aspiration

Unfortunately, John developed aspiration pneumonia, a type of infection, after his choking episode and he was treated at home with antibiotics. John's caregivers recognized the signs of aspiration pneumonia.

Signs/Symptoms of Aspiration

- ❖ Sudden coughing/wheezing
- ❖ Breathing pattern changes
- ❖ Excessive clearing of the throat
- ❖ Drooling
- ❖ Gurgling sound in voice after eating

(Georgia Department of Behavioral Health and Developmental Disabilities, n.d.)

Medical/Behavioral Causes of Aspiration

- ❖ Eating too quickly
- ❖ Dental problems
- ❖ Difficulty with head/neck muscle control
- ❖ Decreased consciousness/awareness
- ❖ Swallowing difficulties

(Baker, 2023a)

Screening for Swallowing Difficulties (Dysphagia)

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(Mayo Clinic, 2022)

Aspiration Prevention

- ❖ Ensure dental problems are cared for.
- ❖ Consider a swallow study to be performed by a speech therapist to determine the level of aspiration risk.
- ❖ Modified diets like mechanical soft or pureed may be ordered for those individuals who are at risk for aspiration.
- ❖ Consider the medications an individual takes that may impair their swallowing ability such as sedatives, muscle relaxers, and opioids.
- ❖ Observe if an individual is eating too much too quickly.
- ❖ Report signs of difficulty swallowing to all caregivers and the healthcare provider.
- ❖ Document any difficulties with swallowing, and any observation of changes from the individual's baseline.

(Baker, 2023a)





The Fatal Five: Dehydration

Let's examine some things to be watchful for while John recovers at home. While recovering at home, he had a fever, and he did not feel well enough to eat or drink. What other Fatal Five conditions is he at risk for? If you answered dehydration and constipation, you are correct! Let's take a closer look at dehydration.

Signs/Symptoms of Dehydration

- ❖ Dry mouth
- ❖ Headache
- ❖ Dizziness
- ❖ Lethargy, difficult to arouse
- ❖ Muscle cramps/weakness
- ❖ Decreased urination
- ❖ Dark concentrated urine

Medical/Behavioral Causes of Dehydration

- ❖ Increased urination
- ❖ Diarrhea/vomiting
- ❖ Not eating or drinking along with a fever can cause loss of fluids in the body which is greater than the amount taken in
- ❖ Excessive sweating

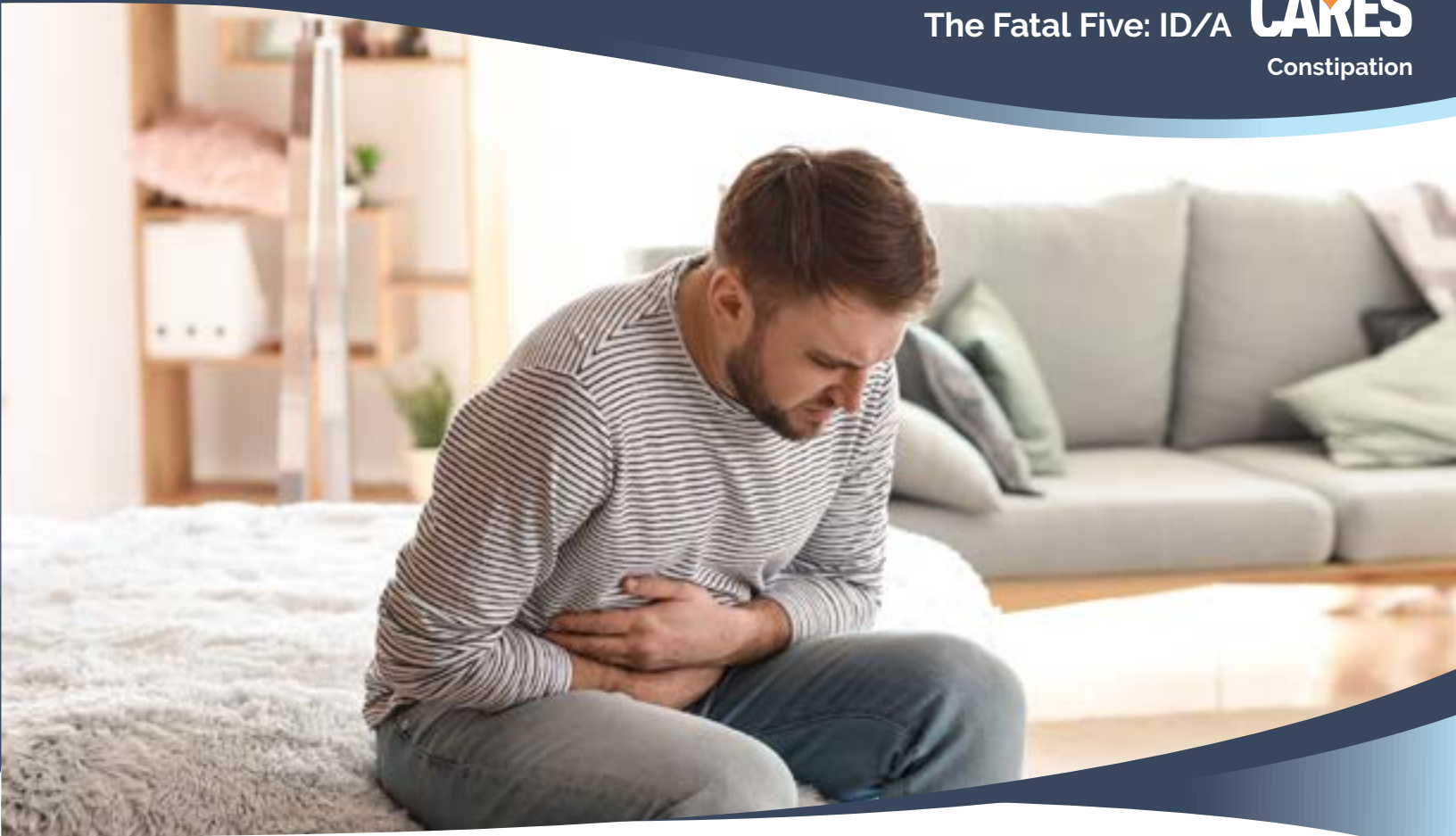
Dehydration Prevention

- ❖ Offer fluids throughout the day.
- ❖ Offer creative types of fluids such as Jello, popsicles, or soup.
- ❖ Increase fluids as tolerated due to fever.
- ❖ Contact the physician when ill to inquire about increasing fluid amounts.
- ❖ Use a fluid record to document the amounts of and types of fluid taken in each day.
- ❖ Observe for symptoms of dehydration.
- ❖ Report signs of dehydration to all caregivers and the healthcare provider.
- ❖ Document any observations from the individual's baseline that may indicate dehydration.

“One of the best ways to prevent dehydration is to be a role model and drink fluids throughout your shift.”

(Kepro HCQU, Fatal Five Training, 2021)





The Fatal Five: Constipation

When John was recovering from home, he had a fever and did not feel well enough to eat or drink. John is at risk for constipation. Let's take a closer look.

Signs/Symptoms of Constipation

- ❖ Hard dry stools
- ❖ Infrequent bowel movements
- ❖ Straining on the commode
- ❖ Sensation like you still must move your bowels
- ❖ Abdominal bloating/pain
- ❖ Liquid stools

(Baker, 2023b)

Medical/Behavioral Causes of Constipation

- ❖ Dehydration
- ❖ Lack of dietary fiber
- ❖ Some medications
- ❖ Advanced age
- ❖ Hospitalization/surgery
- ❖ Inactivity
- ❖ Lack of muscle tone/function

(Baker, 2023b)

Constipation Prevention

- ❖ Encourage fluids.
- ❖ Encourage a healthy diet that contains plenty of fiber.
- ❖ Encourage physical activity as tolerated.
- ❖ Encourage regular bowel habits.
- ❖ Consider speaking to the health care provider regarding probiotics and stools softeners as needed.
- ❖ Observe and report signs of constipation to all caregivers and healthcare provider.
- ❖ Document any observations of changes from the individual's baseline that may indicate constipation.

(Baker, 2023b)





The Fatal Five: Seizures

For a person with a known seizure disorder, illness can affect how well the seizures are controlled and one may see an increase in seizure activity. It is a best practice standard to watch for increased seizure activity when the person is ill. John's caregivers know to stay vigilant during his recovery and to be aware of factors that may cause him to have a seizure. Even if John has been seizure free for a long period of time, aspiration pneumonia may increase his chance of having a seizure.

Signs/Symptoms of Seizures

- ❖ Staring
- ❖ Jerking movements of the extremities
- ❖ Possible loss of consciousness
- ❖ Emotional changes
- ❖ Cognitive changes

(Mayo Clinic, 2023)

The above are general seizure symptoms. It is very important to know the specifics of the individual's seizure diagnosis, because each person's seizure symptoms may be different depending on the type of seizure.

Medical/Behavioral Causes of Seizures

- ❖ Physical stress of being sick
- ❖ Fever
- ❖ Inadequate or lack of effective sleep
- ❖ Not being able to take anti-seizure medication
- ❖ Medication for illness may have unwanted side effects that could trigger seizure activity

(Mayo Clinic, 2023)

While John is healing from the infection caused by aspirating, his caregivers will be working hard towards his recovery. As stated earlier, seizure activity can be more prevalent in individuals when they are ill. John's caregivers can help prevent him from having a seizure by:

Seizure Prevention

- ❖ Ensure anti-seizure medications are taken as prescribed.
- ❖ Be mindful of common triggers: flashing lights, loud noises, or strong odors.
- ❖ Note warning signs of seizures.
- ❖ Be mindful of the temperature of the environment.
- ❖ Encourage rest and sleep when needed.
- ❖ Treat fevers, according to physician orders.
- ❖ Manage stress.
- ❖ Observe and report details regarding seizure activity to the care team and health care provider.
- ❖ Document any details regarding seizure activity.





If John's illness causes him to have a seizure, his caregivers should follow agency protocol for seizure activity. Some of the actions that may be considered are:

Seizure Safety Tips

- ❖ **Check for risk factors that may cause harm during a seizure such as stairs, hard surfaces and furniture that may have square corners such as tables and television stands.**
- ❖ **Discourage baths. Unless they are bed baths, submersion in water, even a very small amount, can be very dangerous during a seizure.**
- ❖ **Prevent further aggravation of illness by preventing choking or aspiration during seizure.**
 - Lower person to the floor
 - Turn the person on their side
- ❖ **Do not restrain. Attempting to hold someone still during seizure activity may cause injury.**
- ❖ **Report and document any details regarding seizures, such as:**
 - Length of seizure
 - Behavior during seizure
 - Noticeable triggers

- Recovery details
- ❖ **Be supportive after the seizure:**
 - Do not force food or beverages or physical activities immediately after seizure.
 - It is best practice to stay near an individual after a seizure until they are feeling closer to their baseline.

(Baker, 2023c)

IF AN INDIVIDUAL EXPERIENCES

- A seizure lasting longer than 5 minutes
- Multiple seizures extremely close together
- A seizure while in water
- A seizure where they stop breathing

These situations are a medical emergency! Call emergency medical services (911) immediately!



COMMUNICATION AND DOCUMENTATION: RISK MITIGATION

Missed opportunities for communication between caregivers can create an unwelcome opportunity for any of the Fatal Five conditions to occur. Effective communication between caregivers is vital in mitigating this risk and a breakdown could lead to an adverse event occurring. Communication should occur throughout the caregiver's shift and to the oncoming shifts. This communication may include changes from the individual's baseline, including physical and behavioral health changes. It may also include new medications, new treatments, or new guidelines from the person's healthcare providers.

LET'S TAKE A LOOK AT THIS SCENARIO:

Caregivers note that while John is eating his dinner, he is drooling and at times holding the food in his mouth. Caregivers also notice with every bite that he is coughing and when he talks his voice sounds hoarse. They suspect John is having difficulties with swallowing. The caregivers have communicated verbally to one another about John's changes. What could they do additionally?

If your answer included for caregivers to document the information and share with the individual's health care provider, then you would be correct. Accurate documentation and communication with all caregivers is essential to ensure an individual receives proper care; it is a means to share all critical information related to the individual's condition with all who need to know. This may include other caregivers, the individual's provider agency, supports coordinator, medical professionals, family, and all other care team members. Information to document may include changes in the individual's baseline, physical and behavioral health changes, new medications, new treatments, or new guidelines from the individual's healthcare providers. Follow the provider agency's policies regarding communication and documentation guidelines.

As you can see, communication and documentation are key in decreasing the risk of John experiencing an adverse event resulting from a Fatal Five condition



FATAL FIVE EDUCATION: PROMOTING POSITIVE OUTCOMES FOR PEOPLE WITH ID/A

The Fatal Five are a combination of conditions that may be prevented when caregivers are proactive and educated on the signs and symptoms that may lead to severe illness. Not all conditions can be prevented, but when caregivers are educated and utilize the tools and resources that are provided throughout this newsletter, the risk of an individual experiencing severe illness may be reduced, leading to quality of life and positive outcomes for the person. The Kepro HCQU offers instructor-led Fatal Five training via Microsoft Teams, as well as online training which may be requested through our website at <https://hcqu-training.kepro.com/content/pages/logon.aspx> (Kepro HCQU, 2021).

Let's see what happened with John when he had one Fatal Five condition and was cared for by caregivers who knew how to prevent the other Fatal Five conditions...

John has made a full recovery, is back at baseline and healthy. His caregivers were educated on the Fatal Five, took the time to recognize what could happen, looked for signs, reported their observations, and took quick action. Because of the caregivers' quick action, John did not experience all Fatal Five conditions at the same time.

REFERENCES:

- Baker, J. (2023a, February 1). The Fatal Five in IDD: Aspiration's Dangers and Key Interventions. Relias. Retrieved February 27, 2023, from <https://www.relias.com/blog/the-fatal-four-aspiration-dangers-and-key-interventions>
- Baker, J. (2023b, February 1). The Fatal Five in IDD: How Constipation Impacts Health. Relias. Retrieved February 27, 2023, from <https://www.relias.com/blog/the-fatal-four-how-constipation-impacts-health>
- Baker, J. (2023c, February 1). The Fatal Five in IDD: What You Need to Know About Seizures. Relias. Retrieved February 27, 2023, <https://www.relias.com/blog/the-fatal-four-what-you-need-to-know-about-seizures>
- Center for Disease Control and Prevention. (n.d.). Prevention. Retrieved February 27, 2023, from https://www.cdc.gov/pictureofamerica/pdfs/picture_of_america_prevention.pdf
- Georgia Department of Behavioral Health and Developmental Disabilities (n.d.) What You Need to Know about Choking and Aspiration. Retrieved February 27, 2023, from https://dbhdd.georgia.gov/sites/dbhdd.georgia.gov/files/related_files/site_page/Choking%20and%20Aspiration%20Fact%20Sheet.pdf
- Kepro HCQU, Fatal Five Training, 2021.
- Mayo Clinic. (2022, September 20). Dysphagia. Retrieved February 27, 2023, from <https://www.mayoclinic.org/diseases-conditions/dysphagia/symptoms-causes/syc-20372028>
- Mayo Clinic. (2023, February 4). Seizures. Retrieved February 27, 2023, from <https://www.mayoclinic.org/diseases-conditions/seizure/symptoms-causes/syc-20365711>