HCQU CARES
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In this Issue:
- Introduction: 2
- Choking and Aspiration: 3
- Constipation: 6
- Dehydration: 9
- Seizures: 11
- Conclusion: 14
Introduction

The Pennsylvania Office of Developmental Programs (ODP), the Massachusetts Department of Developmental Services (DDS), The American Network of Community Options and Resources (ANCOR), and other state and federal agencies have identified four medical conditions that commonly present in people with intellectual and developmental disabilities (I/DD) and have led to serious illness, injury, and even death. These conditions – choking/aspiration, dehydration, constipation, and seizures – are known as The Fatal Four. Complications from these conditions are considered preventable, and education about the fatal four is key to increasing health and safety for people with I/DD.

Richard was a 33-year-old young man with Down syndrome. In 2012, Richard died from unmanaged constipation, and his sister wrote an article describing what occurred. Caregivers reported that Richard was withdrawn and distressed; both his psychiatrist and general practitioner evaluated him and attributed his change in behavior to a mental health concern. However, Richard was in need of medical attention for complications related to constipation. Before he died, over 22 pounds of stool was removed from Richard’s bowel. Treatment was not enough to save him, as the impaction persisted. He eventually aspirated stomach contents and died. Following his death, an autopsy revealed Richard’s bowel was 18 cm (7 inches) in diameter – more than double the average diameter of a large intestine, which is 7.6 cm (3 inches). His sister wrote, “When Richard left home, assessment reports by professionals said very clearly that his constipation would always need close monitoring and support and that constipation should always be considered as a potential cause, when his mental health deteriorated. Somehow, this knowledge was lost over the years.”

While constipation is known as a common problem that causes discomfort, hemorrhoids, and changes in behavior, it is rarely thought of as a cause of death. Sadly, all of the fatal four conditions can lead to severe consequences, including death, when not recognized and treated.

This special edition of the HCQU CARES newsletter provides insight as to why people with I/DD are at risk for the fatal four conditions and how to prevent related complications, including death, from occurring. It offers information and tools to assist caregivers to recognize the signs of each of the conditions, learn prevention strategies, and know what to do if it is suspected that someone has one of these conditions.

Reference:

Choking and aspiration (breathing fluids into the lungs) often are caused by difficulty with swallowing and have led to illnesses, infections, and sometimes death. The following factors increase the risk of choking and aspiration in people with I/DD:

- Disorders of the brain and nervous system, such as cerebral palsy, brain injury, dementia, seizures
- Polypharmacy (multiple medications), with side effects and/or interactions that might cause
  - Dry mouth
  - Changes in muscle movement
  - Extrapyramidal syndrome (a movement disorder)
  - Changes in the nervous system
  - Irritation of issues in the esophagus
- Low muscle tone
- Gastroesophageal reflux disease (GERD)
- Decayed or missing teeth (Klaehn, n.d.)
- Feeding tube
- Tracheostomy (person breathes through a hole in the throat) (Cherpes, 2018)
- Poor eating habits
  - Eating quickly
  - Placing large amounts of food in the mouth
  - Eating non-food items (pica)
  - Choosing not to wear dentures
  - Poor posture during meals
  - Inducing vomiting during or after meals
- Meals

Common signs a person has difficulty with swallowing and is at risk for choking and aspiration:

- Coughing or excessive drooling while eating
- Frequent throat clearing while eating
- Hitting chest
- Shortness of breath while eating, noisy breathing
- Person states the “food is stuck” or “went down the wrong pipe”
- Complaint of pain while swallowing
- Decrease in appetite and weight loss

The Fatal Four

CHOKING AND ASPIRATION
Signs of choking

• Anxious or agitated state
• Red face
• Difficulty breathing
• Noisy breathing
• Severe coughing or gagging
• Hands on throat
• Unable to talk or breathe
• Skin, lips, and nails appear gray or blue
• Loss of consciousness (Cherpes, 2018)

Choking is a medical emergency!

There is no need to obtain approval from a supervisor to call 911 in this emergency. (Cherpes, 2018)

• Immediately begin abdominal thrusts.
• Call 911. (If another person is present, direct him or her to call 911.)
• If the person loses consciousness,
  ○ Lower the person to the floor.
  ○ Call 911 immediately! (If another person is present, direct him or her to call 911.)
  ○ Begin CPR.
• Afterward, notify the person’s physician of choking event. (Klaehn, n.d.)

Be proactive by helping to identify who is at risk for choking. If a person shows signs of having difficulty with swallowing, notify other caregivers so strategies to decrease the risk of choking can be put into place immediately.

ACTIVE SUPERVISION is important during all meals and snacks. Active supervision is looking at the person’s face and watching them chew and swallow to identify signs of choking or difficulty swallowing. Before serving foods and fluids, check the person’s care plan and follow instructions for specific consistency. Never leave the person alone with food or fluids that are of a different consistency.

Additional strategies for caregivers to prevent choking and aspiration

• Offer 30-minute rest periods before meals and snack times to foster a calmer mood while eating.
• Turn off the TV while eating to allow the person to focus on chewing and swallowing.
• Encourage the person to sit at an upright 90-degree angle, unless otherwise recommended. (This includes people who eat in bed.)
• Assist with use of adaptive utensils during all meals and snacks, according to care plan.
• Ensure dentures are in place and fit properly.
• Encourage small bites of food; consider offering a smaller size fork or spoon for a person who places large amounts of food in mouth.
• Encourage sips of fluids between bites of food.
• Offer gentle reminders to eat at a slower pace.
• Schedule adequate time for eating so the person does not feel rushed finish.
• Encourage the person to swallow food before speaking.
• Report signs of difficulty with swallowing to the person’s healthcare provider (Klaehn, n.d.).
Strategies for feeding individuals unable to feed themselves

- Sit down facing the person; do not stand while feeding.
- Offer small bites of food and sips of fluids.
- Ask the person questions after they swallow food.
- Carefully place food in the person’s mouth in a way that minimizes difficulty with swallowing. Proper placement is determined by the cause of the difficulty. For example, if a person has weakness on the right side, food should be placed in the left side of the mouth.

When supporting a person who has a feeding tube, assist the person to maintain an upright position of 30-45 degrees during and for one hour following feeding to prevent formula from flowing up and into the lungs (American Gastroenterological Association, 1994).

Choking and the Elderly

People who are elderly have a greater risk for choking and aspiration due changes that occur with aging.

- Decrease in muscle strength and coordination can interfere with proper chewing and swallowing.
- Teeth often become weak or are absent.
- Decrease in saliva in mouth and throat can interfere with swallowing (KEPRO HCQU Dysphagia presentation).

*Be proactive and provide ACTIVE SUPERVISION especially for this population.*

One single choking event may be a warning sign for future choking events. Choking may lead to aspiration, infection, and possibly death.

The KEPRO HCQU offers a variety of trainings to assist caregivers to learn more about the risks of choking and aspiration in people with I/DD.

- Aging: Physical Changes and Care
- Aspiration Pneumonia
- Cerebral Palsy
- Dementia
- Digestive Disorders: Lower GI
- Down Syndrome/Trisomy 21
- Dysphagia
- Eating Disorders
- Genetic Syndromes
- Neurological Diseases

References:


The Fatal Four

**CONSTIPATION**

Constipation is defined as having fewer than three bowel movements a week. This is a general definition and may be different from person to person. It is important to identify normal bowel habits in the people you support and to know your agency’s definition and policies.

There are a number of causes for constipation such as:

- Lack of fiber in the diet
- Not drinking enough fluids
- Lack of exercise
- Side effect of medications
- Medical conditions such as diabetes, stroke, spinal cord injuries

In addition to the causes listed above, people with I/DD are more likely to become constipated due to factors specific to their disability, such as:

- Low muscle tone, especially in the abdominal muscles that help move intestinal waste
- Immobility, which reduces movement and prevents gravity from moving stool through the intestine
- Medications with side effect of constipation
- Inability to chew and swallow fibrous foods
- Not enough time to use the toilet, which may decrease the urge to go
- No established bathroom routine; a persistent delay in using the bathroom decreases the urge
- Changes in routine, such as a new residence, day program, or job
- Pain or discomfort making it difficult to get to bathroom in time or sit comfortably on the toilet

Common signs of constipation are a decrease in number of stools, small, hard stools, straining, and sometimes rectal bleeding. In people with I/DD, the signs might be subtle or different from those usually associated with constipation such as:

- Lack of appetite; refusal of meals
- Frequent and/or extended trips to the bathroom
- Avoiding attempts to use the bathroom
- Crying, grimacing, grunting while attempting to move bowels
- Rectal digging
- Hitting abdomen
- Hard, protruding abdomen
- Refusing to participate in activities
If not addressed, constipation can have severe complications, like bowel impaction or obstruction. Symptoms of complications are:

- Firm, larger than normal abdomen
- Seeping watery stool following a period of several days with no bowel movement
- Lack of energy
- Vomiting, which may smell like feces
- Severe abdominal pain
- Possible back pain
- Sweating, rapid pulse, low blood pressure (if untreated may result in shock)

*If these symptoms are noticed, a healthcare provider should evaluate the person immediately.*

Simple steps can be taken to help prevent constipation, including:

- Providing and encouraging fluids throughout the day, especially to those who cannot obtain fluids on their own
- Documenting and reviewing fluids consumed on a daily record if unsure of the amount of fluids the person is taking
- Increasing dietary fiber, while also increasing fluids
  - The article, “Top 10 Sources for Fiber”, can be found on the WebMD website at the following address: https://www.webmd.com/diet/features/top-10-sources-of-fiber
- Consulting with a dietician for meal and snack suggestions when the person is on a fluid restriction or low fiber diet
- Encouraging physical activity most days of the week
- Offering the opportunity for toileting on a routine basis, allowing ample time and privacy
- Providing a small stool to prop the person’s feet and elevate the knees to help relax muscles, as noted in the picture below, to aid in facilitating a bowel movement

- Using a bowel movement record that indicates the size and consistency of each bowel movement
  - The Bristol Stool Chart identifies normal vs. abnormal stools. Search the Bristol Stool Chart on the Internet for a PDF handout
- Documenting each bowel movement ASAP instead of waiting until the end of your shift when it may be forgotten
- Ensuring orders for PRN medications for constipation indicate how many consecutive days with no bowel movement must occur before medication should be given, what action to take if the medication is not effective, and when to notify the physician.
- Checking the bowel movement record daily to determine if a PRN medication is needed
- Documenting the effectiveness of PRN medication

*Consider that many people with I/DD are at risk of constipation. Be proactive and employ preventative strategies for everyone, regardless of whether they are identified as being at risk.*
Constipation and the Elderly

The elderly are at greater risk for constipation due to medical conditions that are prevalent in this age group, such as the following:

- Diabetic neuropathy
- Dementia
- Parkinson’s disease
- Irritable bowel syndrome
- Hemorrhoids

People with I/DD often take many medications that cause constipation, and by the time they reach advanced years, their medication list usually grows longer, increasing chances for the side effect of constipation. Be proactive and follow tips to decrease risk for pain and complications caused by constipation for this aging population.

Constipation can be very serious and lead to a severe impaction that may need to be treated surgically. A fecal impaction may also tear the intestinal wall, seep stool into the abdomen, enter the bloodstream, and cause sepsis.

Caregivers who are interested in learning more about how constipation affects people with I/DD and ways it can be prevented may want to consider the following trainings containing information related to this subject offered by the KEPRO HCQU.

- Aging: Physical Changes and Care
- Behavioral Manifestations of Pain
- Bowel Management
- Dementia
- Down Syndrome/Trisomy 21
- Eating Disorders
- Emergency Care: When to Seek
- Genetic Syndromes
- Neurological Diseases
- Pain Management
- Surgery Care
- Thyroid Disorders

References:


KEPRO HCQU Bowel Management presentation
Dehydration means that the body does not have enough water to function properly. There are many common causes of dehydration, such as:

- Diarrhea and vomiting
- Sweating excessively
- Fever
- Large burns
- Medications that increase urination
- Undiagnosed or uncontrolled diabetes

People with I/DD are at an increased risk for dehydration, especially those who:

- depend on others to feed them during meal and snack times
- use wheelchairs, relying on others to obtain fluids for them
- cannot communicate verbally, or are difficult to understand and unable to communicate clearly that they are thirsty
- take medications that can lead to dehydration, such as those used to control seizures, blood pressure, and behavior. (It is important to read the side effects of medications before administering them. Side effects of medication can be found on the information insert that is given with each prescription or in a medication handbook.)

Common signs of dehydration are dry mouth, headache, dizziness, lethargy, muscle weakness, decreased urination, and dark concentrated urine. Dehydration may also be indicated when a person is difficult to arouse. Severe dehydration symptoms, such as low blood pressure, rapid heartbeat, and lack of sweat, may indicate a medical emergency.

Drinking rapidly, taking drinks from others, and drinking directly from the faucet may be signs of dehydration in people with I/DD, especially if they cannot communicate they are thirsty.

Be proactive to prevent dehydration!

- Give each person a water bottle during to the community, especially when outside on a hot and sunny day
- Remind people with I/DD to drink fluids between meals, throughout the day
- Educate people with I/DD, to their ability of understanding, about the importance of drinking enough fluid every day
- Suggest the 8x8 rule (eight 8oz glasses per day), unless otherwise specified by the person’s physician
- Offer flavored, no calorie water for those who do not like to drink water (please note that plain water is preferred)
- Discourage soda due to the sugar and possible caffeine content
- Discourage caffeinated beverages such as coffee and tea
• Increase fruits and vegetables with a high water content, such as
  ○ Cucumbers, iceberg lettuce, celery, tomatoes, green pepper, cauliflower, spinach
  ○ Watermelon, strawberries, grapefruit, cantaloupe, oranges
• Offer alternative types of fluids such as Jell-O, Popsicles, and soup
• Offer fluids frequently when the person is outside in the sun and before, during, and after exercise
• Increase fluids, as tolerated, when the person is experiencing fever, diarrhea, and vomiting
• Contact the physician ask if fluid amount should be increased when the person is ill
• Offer fluids throughout the day to people who cannot feed themselves, access water independently, and ask for drinks.
• Use a fluid record to record the amount and type of fluid taken each day, when uncertain how much the person drinks

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

Dehydration and the Elderly

The Healthy Aging and Intellectual Disabilities study reports that dehydration/malnutrition was the second most common cause of death in older adults with intellectual disabilities. (Oppewal et al. 2018). Please keep this in mind as people with I/DD are living longer than ever.

The elderly are at risk for dehydration because they may have several chronic medical conditions, may be taking many medications, and may be in frail condition. Also as people age, their bodies’ change, increasing their risk for dehydration. For instance,

• Total body water percentage decreases
• Sense of thirst is reduced and becomes an unreliable indicator of the body’s need for water
• Decreased kidney function interferes with the body’s ability to retain water and sodium

It is important to monitor fluid intake in the elderly to prevent dehydration, especially during illness and warm weather. Keep in mind, the person may not feel thirsty and ask for a drink. A more reliable indicator of proper hydration is to check the color of the person’s urine. Clear or light-colored urine is a sign the person is hydrated.

Remember, dehydration can lead to serious medical complications including death.

Many KEPRO HCQU trainings, such as those listed below, provide information about how to prevent dehydration in people with I/DD.

• Aging: Physical Changes and Care
• Bowel Management
• Dementia
• Digestive Disorders: Lower GI
• Dysphagia
• Eating Disorders
• Emergency Care: When to Seek
• Foodborne Illnesses
• Infectious Diseases: General Infections
• Infectious Diseases: Resistant Organisms
• Surgery Care
• Urinary Tract Infections (UTI)

References:


Seizure activity occurs from abnormal electrical activity in the brain. According to the National Institute of Health, “Epilepsy is more common in people with intellectual disabilities than in the general population.”

The characteristics of seizures vary depending on the area of the brain the disturbance occurs. Such characteristics may include:

- Staring, rapid eye blinking, unresponsiveness
- Twitching of face/extremities, lip smacking
- Change in breathing pattern
- Odd, repetitive behavior
- Shaking, rigid, jerking of extremities
- Body stiffening
- Sudden aggressive behavior
- Bladder or bowel incontinence

Seizures occur for many reasons, but some people may have specific triggers that produce seizure activity. Caregivers can look for a pattern of triggers when seizures occur. Consider these questions...

- Where did the seizure occur?
- What was the person doing before the seizure?
- Was the person sick?
- Do the seizures occur at certain times of the day or month?
- Is the person not sleeping well?
- Was the person experiencing stress?

If the trigger for seizure activity is identified, be proactive and avoid it as much as possible. Common triggers for seizures are:

- Late or missed seizure medication
- High or low blood sugar
- Dehydration
- High fever
- Severe constipation
- Fluctuating hormones around a woman’s menstrual cycle
- Inadequate sleep
- Stress
- Photosensitivity (bright flashing or flickering lights)
- Auditory triggers (loud sounds, sudden sounds that startle)
Specific records and documentation, such as those listed below, may help caregivers and the physician understand what can trigger seizure activity.

- Bowel movement record to identify if the person is constipated
- Fluid record to help ensure the person is hydrated
- Food record to help keep blood sugar stable
- Menstrual record to identify if seizures occur near woman’s menstrual period
- Sleep record to explore if lack of sleep is a trigger

Take time to review the records and take them to the person’s doctor appointments when a pattern is noticed.

Consider this scenario:

Karen was reviewing the seizure record of one of the people in her group home. She then gathered the person’s sleep record, blood sugar document, menstrual record, and bowel movement record and compared them to the times the person had seizure activity. She was surprised to find that the person had seizure activity on the day before and the day of receiving a suppository for constipation. She wrote a plan with strategies to prevent constipation as the person was already taking a stool softener. When this was not successful, she informed the PCP and the person was ordered a different stool softener. Afterward, the person was no longer constipated, and her seizure activity significantly decreased.

Other ways to prevent seizures and keep the person safe include:

- Speaking to the neurologist for specific orders on what to do if seizure medications are missed or administered late. This will eliminate time spent contacting the agency nurse and/or the physician.
- Encouraging nutritious meals and supporting a healthy lifestyle, including proper sleep
- Monitoring the person during showers and baths by standing outside the bathroom
- Encouraging the person to take a shower, using a shower chair, instead of a bath

Always stay with the person throughout the seizure and keep the person safe by:

- Helping the person lie down on the floor or bed if necessary
- Loosening clothing around the person’s neck and removing glasses
- Placing the person on his or her side to allow saliva to drain (this also prevents aspiration if the person vomits)
- Not putting anything in the person’s mouth (they cannot swallow their tongue)
- Not restraining the person (the seizure cannot be stopped)
- Providing padding under the person’s head to prevent a head injury
- Not moving the person unless he or she is in an unsafe area
- Checking for breathing throughout the seizure activity

After the seizure, the person may be very lethargic. Allow the person to rest or sleep as needed and check on him or her frequently. Do not administer medication, or feed or provide fluids, until the person is fully awake.

Most seizures need little intervention; however, there may be times to call 911, such as when:

- It is the person’s first seizure
- The person is not breathing
- The seizure lasts over 5 minutes
- Seizures continue one after another
- A head injury or other bodily injury occurred during the seizure
The seizure occurs in water

Documenting specific seizure characteristics is important because the information can assist the physician to identify the type of seizure the person experienced and provide proper treatment and medications. Using a detailed seizure record designed to document seizure activity is more effective than writing in sentence form what occurred during the seizure. The Epilepsy Foundation provides a seizure record containing a check off list of seizure characteristics that might be noted during seizure activity. It may be found at https://www.epilepsy.com/sites/core/files/atoms/files/event_calendar.pdf

Seizures and the Elderly

According to the Centers for Disease Control and Prevention (CDC), seizures are more likely to occur as people age due to risk factors such as:

- Strokes
- Head injuries
- Brain and nervous systems disorders such as Alzheimer’s disease
- Brain tumors

The CDC reports that approximately half of older people who experience seizures do not know the cause of their seizures. Seizures may also go undetected when occurrences like falls, confusion, memory loss, or sensory changes are attributed to aging, and may really be signs of epilepsy. Seizures occurring in people with I/DD are often unrecognized because the change in the person’s behavior is blamed on their intellectual disability.

Document and report any change in behavior to the physician, especially as individuals age, to ensure a proper evaluation.

*Seizures may be life threatening if the person stops breathing, has an irregular heartbeat during a seizure, or falls and sustains a severe injury.*

More information about seizure activity in people with I/DD can be found in the following KEPRO HCQU trainings:

- Cerebral Palsy
- Down Syndrome/Trisomy 21
- Emergency Care: When to Seek
- Genetic Syndromes
- Medical Facilities: Appropriate Use
- Neurological Diseases
- Seizure Overview

References:


Kepro HCQU Seizure Overview presentation

The Fatal Four (August 1, 2018) Pennsylvania Department of Human Services ppt.
Improving the Life Expectancy of People with I/DD

The KEPRO HCQU hopes caregivers will review this information, understand the harm the Fatal Four can cause, and follow the strategies provided to prevent Fatal Four conditions from occurring. However, there may be people not yet identified as being at risk. Caregivers and agencies should consider asking:

- Is there a method to identify people at risk for the Fatal Four?
- Are precautions or strategies in place to eliminate or reduce the risk?
- Are caregivers educated on these strategies, especially as people in their care are aging?
- Is appropriate documentation being completed to address the safety and health concerns related to the Fatal Four?
- Are processes in place for emergency response and calling 911?

Recognizing and preventing the dangers of these four common conditions that can jeopardize the life of people with I/DD is one of the most important ways caregivers can improve the health and welfare of people they support. The population of adults with I/DD age 60 and older is growing dramatically and is estimated to increase from 850,600 in the community, based on the 2010 US census, to an estimated 1.4 million by 2030, due to increasing life expectancy and the aging of the baby boomer generation (Factor et al., 2012). These four conditions may be seen more frequently as people age. The take home message is that the complications and poor outcomes that can arise from these four conditions are preventable. Caregivers who understand these four conditions and are alert to their signs and symptoms are well prepared to positively impact the health and safety of the people they support.

References:
