

Fall 2018 Issue

“When you are a nurse you know that every day you will touch a life... and a life will touch yours.”



The Fatal Four

As health care providers, nurses are aware of the health concerns for people with intellectual and developmental disabilities (I/DD). However, four major health issues have been identified for people with I/DD that have led to serious illnesses, infections, and sometimes death. These four major health issues, consisting of dehydration, seizures, choking/aspiration, and constipation, are called the Fatal Four. The Office of Developmental Programs (ODP) will be sending health alerts to provider agencies to increase awareness of the dangerous consequences that may result from the Fatal Four, with ways to promote safety to decrease their risk.

Nurses are in the distinguished position to help caregivers understand why people with I/DD are at an increased risk for these four health concerns. They can help caregivers identify who is at risk, and provide education and resources to promote safety and competence in managing the issues and supporting the person.

Dehydration

Dehydration is defined as excessive loss of water from the body. There are many common causes of dehydration, such as:

- Diarrhea and vomiting
- Excessive sweating
- Fever
- Large burns
- Taking medications that increase urination, such as diuretics and anti-hypertensives
- Undiagnosed or uncontrolled diabetes

However, many people with I/DD have specific risk factors. Nurses can help caregivers identify people who depend on them for assistance to stay hydrated, including those who:



- depend on others to feed them during meal and snack times
- use wheelchairs and rely 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 may lead to dehydration such as:
 - Seizure medication (e.g., Zonegran and Topamax can decrease the sweating mechanism causing body temperatures to rise)
 - Diuretics (e.g., Lasix, Spironolactone, Hydrochlorothiazide)
 - Psychotropic medications (e.g., Thorazine, Mellaril, Haldol, and Risperdal can cause decreased sweating and increase the skin's sensitivity to the sun. Caregivers should ensure that everyone wears sunscreen, especially those with an increased risk for sunburn.)
 - Lithium, a medication used to treat psychiatric disorders. Ensure that caregivers are educated in understanding that lithium toxicity is a life threatening condition. Ask the person's healthcare provider the amount of fluid the person should drink each day.

A resource for the signs and symptoms of lithium toxicity and prevention is <https://www.drugs.com/cg/lithium-toxicity.html>.

The 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.

People with I/DD may also exhibit behaviors such as drinking rapidly, taking drinks from others, and drinking directly from the faucet.

Nurses can encourage caregivers to be proactive in preventing dehydration by:

- Give each person a water bottle during community trips, especially when outside on a hot and sunny day
- Reminding the person to drink fluids between meals throughout the day
- Educating the person with I/DD, to their ability of understanding, about the importance of drinking enough fluid every day

- Suggesting the 8x8 rule (eight 8oz glasses per day), unless otherwise specified by the person's physician
- Offering flavored, no calorie water for those who dislike drinking water (keep in mind that regular water is preferred)
- Discouraging soda due to the sugar and possible caffeine content
- Discouraging caffeinated beverages such as coffee and tea
- Increasing fruits and vegetables with a high water content
- Offering alternative types of fluids such as Jell-O, Popsicles, and soup
- Offering fluids frequently when the person is outside in the sun and before, during, and after exercise
- Increasing fluids, as tolerated, when the person is experiencing fever, diarrhea, and vomiting
- Contacting the physician to inquire about increasing fluid amount when the first signs of illness are observed
- Offering fluids to people who cannot feed themselves, access water independently, and do not have the verbal ability to ask for drinks.
- Using a fluid record to record the amount and type of fluid taken each day, when uncertain how much the person drinks
- Suggesting they be a role model and drink fluids throughout their 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)

The elderly are at risk for dehydration due to multi-morbidity, polypharmacy, and general frailty.

As people age, physiological changes occur that also increase their susceptibility to dehydration. For instance,

- Total body water percentage is decreased
- 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

Caregivers must understand that monitoring fluid intake in the elderly, especially during illness and warm weather, is important to prevent dehydration in this population. A reliable indicator of proper hydration is clear or light colored urine.

Remind caregivers that dehydration can lead to serious physical complications, including death.

Nurses can also provide resources for caregivers to review. The following Mayo Clinic web address provides easy-to-understand information about the symptoms, causes, risk factors, complications, and prevention of dehydration: <https://www.mayoclinic.org/diseases-conditions/dehydration/symptoms-causes/syc-20354086>

References:

Klaehn, R. (n.d.). *Persons with a developmental disability are at risk for dehydration!* Retrieved from https://des.az.gov/sites/default/files/qanewsletter_dddpreventionseries_1.pdf

Oppewal, A., Schoufour, J. D., Van der Maarl, H. J., Evenhuis, H. M., Hilgenkamp, T. I., & Festen, D. A. (2018). *Causes of Mortality in Older People With Intellectual Disability: Results From the HA-ID Study.* *American Journal on Intellectual and Developmental Disabilities, 123*(1), 61-71. doi:10.1352/1944-7558-123.1.61

Schols, J. M., Groot, C. P., Cammen, T. J., & Olde Rikkert, M. G. (2009). *Preventing and treating dehydration in the elderly during periods of illness and warm weather.* *The Journal of Nutrition, Health and Aging, 13*(2), 150-157. doi:10.1007/s12603-009-0023-z

Constipation

There are many causes of constipation. Some include:

- Lack of fiber in the diet
- Inadequate fluid intake
- Lack of exercise
- Medication side effect
- Medical conditions such as diabetes, stroke, and spinal cord injuries

People with intellectual and developmental disabilities (I/DD) are more likely to become constipated from these causes, as well as others specific to their disability, such as:

- Hypotonia, especially in the abdominal muscles that help facilitate peristalsis
- Immobility, which reduces the movement and gravity that aids in moving stool through the intestine
- Polypharmacy with side effects of constipation
- Inability to chew and swallow fibrous foods
- Insufficient time to use the toilet, which may decrease the urge to have a bowel movement
- Unestablished bathroom routine (delays in using the bathroom decreases urge to have a bowel movement)
- Changes in routine such as moving to a new residence, attending a new day program, or starting a new job
- Inability to move quickly to the bathroom or sit comfortably on the toilet because of pain or discomfort

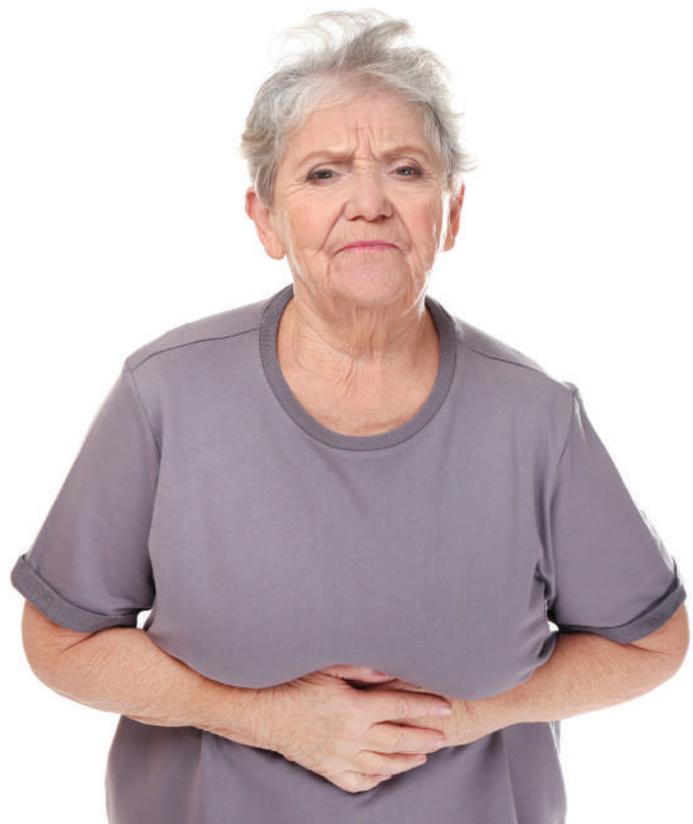
The common signs of constipation include a decrease in number of stools, small, hard stools, and straining. Rectal bleeding is also possible. People with I/DD may exhibit other subtle symptoms, or symptoms not usually associated with constipation such as:

- Lack of appetite/refusal of meals
- Constant trips to the bathroom/staying in the bathroom for an extended period of time
- Avoiding use of the bathroom (due to pain experienced when moving bowels)
- Crying, grimacing, grunting while attempting to have a bowel movement
- Rectal digging
- Hitting the abdomen
- Refusing to participate in activities

Unaddressed or unrecognized signs of constipation can lead to severe complications such as an impaction and/or obstruction.

Symptoms to be aware of are:

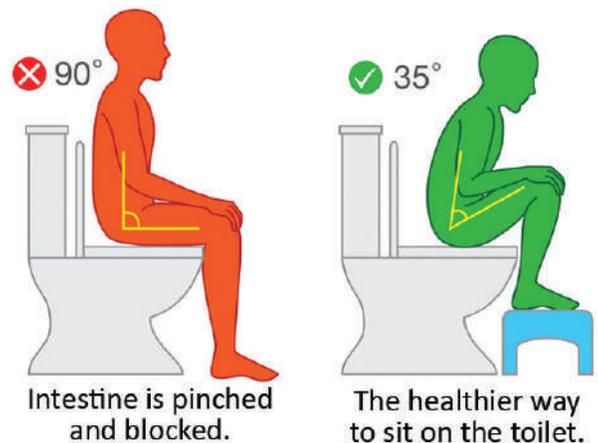
- Firm, distended abdomen
- Seeping watery stool following a period of several days with no bowel movement
- Lack of energy
- Vomiting that may smell like feces
- Severe abdominal pain
- Possible Back pain
- Sweating, rapid pulse, hypotension (may result in shock if untreated)



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

Nurses can encourage caregivers to follow these simple steps to help prevent constipation in people they support:

- Provide and encourage fluids throughout the day, especially to those who cannot obtain fluids independently
- Document fluids on a daily record if unsure of the amount of fluids the person is taking
- Increase dietary fiber, while also increasing fluids
 - The article, “Top 10 Sources for Fiber”, is found on the WebMD website at the following address: <https://www.webmd.com/diet/features/top-10-sources-of-fiber>
- Consult with a dietitian for meal and snack suggestions if the person is on a fluid restriction or low fiber diet
- Promote physical activity most days of the week
- Offer the opportunity for toileting on a routine basis, allowing ample time and privacy
- Provide a small stool to prop the person’s feet and elevate the knees, as noted in the picture below, to help relax muscles and aid in facilitating a bowel movement.
- Ensure 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.
- Utilize a bowel movement record that indicates the size and consistency of each bowel movement
 - The Bristol Stool Chart identifies normal vs. abnormal stools. Search Bristol Stool Chart on the Internet for the PDF handout.
- Encourage a daily check of the bowel movement record to determine if a PRN medication is needed
- Emphasize the importance of bowel movement documentation
 - Documenting each bowel movement is of utmost importance
 - Document the effectiveness of PRN medication
- Consider that many people with I/DD are at risk for 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
- Electrolyte imbalances – hypokalemia, hypercalcemia
- Irritable bowel syndrome
- Obstructions/stenosis from tumors, hernia
- Hemorrhoids

Polypharmacy is also prevalent in elderly people with I/DD. Remind caregivers of the increased risk of constipation in this age group. Encourage them to be proactive, and implement strategies to decrease the risk of pain and complications that can occur from constipation.

Remind caregivers that constipation can be serious and lead to a severe impaction. A fecal impaction may tear the intestinal wall, seep stool into the abdomen, enter the bloodstream, and cause sepsis.

The following Mayo Clinic web address provides an overview of constipation and ways to prevent it. Nurses can print the information and offer it to caregivers to assist in reducing the risk of constipation.

<https://www.mayoclinic.org/diseases-conditions/constipation/symptoms-causes/syc-20354253>



References:

Cateora, D. (n.d.). Self-study program -0723C: Constipation. Retrieved August 8, 2018, from <https://www.oregon.gov/DHS/SENIORS-DISABILITIES/PROVIDERS-PARTNERS/Documents/0723C-Constipation-Modified.pdf>

De Giorgio, R., Ruggeri, E., Stanghellini, V., Eusebi, L. H., Bazzoli, F., & Chiarioni, G. (2015). Chronic constipation in the elderly: a primer for the gastroenterologist. *BMC Gastroenterology*, 15(1). doi:10.1186/s12876-015-0366-3

KEPRO HCQU Bowel Management presentation

Choking and Aspiration

Dysphagia is a serious health concern in people with intellectual and developmental disabilities (I/DD). Choking and aspiration resulting from difficult swallowing have led to illness, infections, and sometimes death. There are many reasons this health risk may be widespread in this population:

- Neurological disorders such as cerebral palsy, brain injury, dementia and seizures
- Polypharmacy, with many side effects and interactions between medications causing
 - Dry mouth
 - Smooth muscle function changes
 - Extrapyrimalidal syndrome
 - CNS depression
 - Irritated esophageal mucosa
- Low muscle tone
- GERD
- Decayed or missing teeth
- Feeding tubes
- Tracheostomies
- Poor eating habits such as,
 - Eating fast
 - Placing large amounts of food in the mouth
 - Pica
 - Choosing not to wear dentures
 - Poor posture during meals
 - Inducing vomiting during or after meals

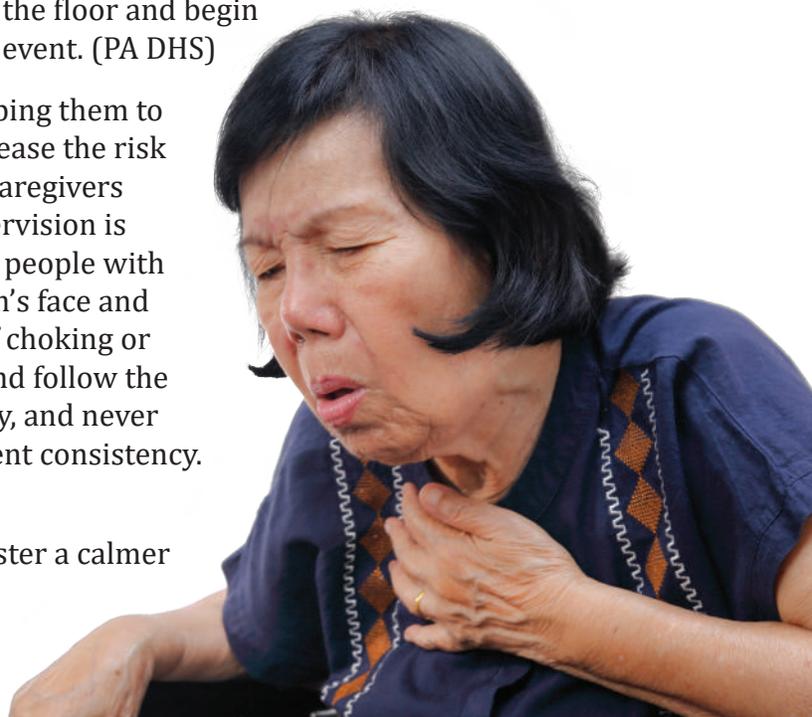
Common signs of dysphagia that may lead to choking and aspiration are:

- 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
- Anxious or agitated state
- Putting hands on throat
- Decreased appetite and weight loss

When an individual is choking, caregivers should call 911 immediately. There is no need to receive approval from a supervisor in this emergency. Initiate first aid (abdominal thrusts) and if the person becomes unresponsive, carefully lower him or her to the floor and begin CPR. Notify the healthcare provider of every choking event. (PA DHS)

Nurses can educate caregivers to be proactive by helping them to identify who is at risk for choking. Strategies to decrease the risk of choking can be immediately implemented. Teach caregivers the importance of ACTIVE SUPERVISION. Active supervision is important during all meals and snacks, especially for people with dysphagia. Active supervision is looking at the person’s face and watching them chew and swallow to identify signs of choking or swallowing difficulty. Caregivers should also check and follow the person’s orders for specific food and fluid consistency, and never leave the person alone with foods that are of a different consistency. Caregivers can also:

- Offer 30 minute rest periods before eating to foster a calmer mood during meals



- Turn off the TV during meals so the person may better focus on chewing and swallowing
- Encourage the person to sit at an upright, 90-degree angle, unless otherwise recommended. This includes those eating meals in bed
- Remember to use the person's adaptive utensils during meals and snack times
- Ensure dentures are in place and fit properly
- Encourage small bites of food; consider using a smaller size fork or spoon for a person who places a large amount of food in his or her mouth
- Encourage sips of fluids in between bites of food
- Give reminders to eat at a slower pace
- Provide plenty of time to finish meals so the person does not feel rushed
- Encourage the person to swallow food before speaking

Teach caregivers how to safely feed a person who is unable to feed himself or herself. This may include sitting down, instead of standing, and facing the person while feeding. Offer small bites of food and sips of fluids during meals. Ask the person questions after they swallow food. Place food in the person's mouth in a way that avoids triggering the type of chewing/swallowing problem the person has. For example, if the person has right-sided weakness, place the food in the left side of the mouth.

When caring for people with feeding tubes, nurses can remind caregivers to keep the person in an upright, 30-45 degree position during, and one hour after, feeding.

Take a few minutes to observe individuals during meals and encourage caregivers to follow the above approaches to reduce the risk of choking and aspiration. Report symptoms of dysphagia to the healthcare provider.

Choking and the Elderly

Elderly people who have complex medical diagnoses are at risk for choking and aspiration. Physiological changes also increase risk. For instance,

- Muscles tend to lose strength and coordination over time, which may interfere with proper chewing and swallowing capabilities
- Teeth often become weak or are absent
- Mucosal surfaces in the mouth and throat become less moist, causing difficulty in swallowing

Caregivers can be encouraged to be proactive and provide ACTIVE SUPERVISION, especially for this vulnerable population.

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

Nurses can provide caregivers with a copy of ODP's handout, "Choking: Medical Emergency Health Alert" sent to providers in August.

References:

Klaehn, B. (n.d.). *Clinical practice guideline: Assessing risk of dysphagia and choking*. Retrieved from https://mfprac.com/web2018/07literature/literature/Gastroenterology/Dysphagia_Klaehn.pdf

Cherpes, G. (n.d.). *Health Alert Choking: A Medical Emergency*. Pennsylvania Department of Human Services

American Gastroenterological Association. (n.d.). Retrieved from <http://www3.us.elsevierhealth.com/gastro/policy/v108n4p1280.html>

KEPRO HCQU Dysphagia presentation

Seizures

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. Encourage caregivers to explore the reasons or triggers for seizures and to be proactive in avoiding them as much as possible. Common triggers for seizures include:

- Late or missed anti-epileptic medication
- Hypoglycemia/hyperglycemia
- Dehydration
- High fever
- Polypharmacy
- Severe constipation
- Fluctuating hormones around woman’s menstrual cycle
- Inadequate sleep
- Stress
- Photosensitivity (bright flashing or flickering lights)
- Auditory triggers (loud sounds, sudden sounds that startle)

Nurses can assist caregivers to manage seizures in people they support.

- Nurses can assist caregivers to manage seizures in the people they support by encouraging them to:
- Contact the neurologist for standing orders on how to proceed when seizure medications are missed or administered late. This will eliminate time spent contacting the agency nurse and/or the physician.
- Offer nutritious meals and support a healthy lifestyle, including proper sleep
- Ask the person to consider showering, with the aid of a shower chair, instead of taking a bath



- Monitor the person during showers by standing outside the bathroom
- Maintain specific records and documentation to help caregivers and physicians understand what may trigger seizure activity. Such records may include:
 - Bowel movement record to identify if the person is constipated
 - Fluid record to 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

Remind caregivers to stay with the person throughout the seizure and to keep him or her safe by:

- Helping the person lie down on the floor or bed if necessary
- Loosening clothing around the person's neck and removing his or her glasses
- Placing the person on his or her side
- Not placing anything in the person's mouth
- Not restraining the person
- Providing padding under the person's head
- Not moving the person unless the area is unsafe
- 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 at frequent intervals. 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. Nurses can advocate for a comprehensive seizure record to record seizure activity rather than caregivers documenting in sentence form what occurred during the seizure. The Epilepsy Foundation provides a seizure record using a check off list of characteristics noted during seizure activity. This can be found by going to: 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
- Neurodegenerative 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. For people with I/DD, seizures are often unrecognized because the person's change in behavior is blamed on their intellectual disability.

Caregivers can be encouraged to observe, document, and report any behavior changes in the people they care for, especially in those who are aging, to the physician to ensure a proper evaluation.

Remind caregivers that seizures may be life threatening if the person stops breathing, has an irregular heart beat during a seizure, or falls and sustains a severe injury.

The Epilepsy Foundation provides a wealth of information on the various types and characteristics of seizure activity, along with ways to support a person with epilepsy. Their website is <https://www.epilepsy.com/>.

References:

Robertson J, et al. (n.d.). *Prevalence of epilepsy among people with intellectual disabilities: A systematic review*. - PubMed - NCBI. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/26076844>

State of New Jersey Department of Human Services. (n.d.). Retrieved from <https://www.state.nj.us/humanservices/news/publications/DDD%20seizures%20bulletin.pdf>

Centers for Disease Control and Prevention. (2018, May 15). *Epilepsy and Older Adults*. Retrieved from <https://www.cdc.gov/features/epilepsy-older-adults/index.html>

KEPRO HCQU Seizure Overview presentation

The Fatal Four (August 1, 2018) Pennsylvania Department of Human Services ppt.

The KEPRO HCQU looks forward to helping agencies recognize and prevent The Fatal Four common medical conditions that can cause serious illness or death. A Special Edition of the HCQU Cares Newsletter for caregivers will be forwarded to agencies in coordination with this Fall Nurse Newsletter. When time allows, encourage questions and offer suggestions when making rounds and visiting people under your care. Together we can all make a difference to improve the health care and quality of life for people with intellectual and developmental disabilities.



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