

Developmental Disabilities Nursing Manual Companion Guide

Protocols and Guidelines

Protocols are written instructions for caregivers to follow when individuals have specific or frequent problems from a health concern that usually has a predictable outcome. Protocols give guidance to caregivers on signs and symptoms to look for, when and how to intervene and who to notify.

Protocols are sometimes confused with procedures.

Procedures are task oriented. They provide step-by-step instructions on how to do a task. For example: "how to administer a gastrostomy feeding" or "how to empty a Foley catheter bag."

Protocols are problem oriented. They explain what to do about a health problem. They contain a description of the problem, when and how to intervene, when to call 911 and who to notify.

Protocols need to be specific to the setting and the individual. For instance, if three individuals living in the same home have seizure protocols, they should all read differently. There will be some similarities, such as basic safety guidelines and documentation requirements, but each should have a specific seizure description and may vary on when to call 911. Protocols need to be specific to the setting. An individual's seizure protocol for the home should read slightly differently than their protocol for the vocational site.

Protocols need to identify the author(s) (see ISP rules regarding documenting author of protocol). If an individual has a nurse involved in his/her care, the nurse will usually write the protocols involving health concerns with input from caregivers. Occasionally, a physician may write directions on how to deal with a specific health

issue, such as when to notify him/her if a person has a low or high blood glucose level. These directions should be included in the protocol, but are inadequate as a complete protocol. If the individual does not have a nurse involved in their care, someone knowledgeable about the individual and health issues should write the protocols. This is likely to be the health manager, house manager, program director or foster provider. The author(s) of the protocol should be clearly identified.

Protocols need to be dated and reviewed periodically. As the individual's condition changes, the protocols should be updated. When physician orders are changed, protocols may need to reflect those changes. For example, if an individual's constipation protocol instructed the caregivers to start monitoring all bowel movements, the protocol would have to be revised. Any changes made to the protocol need to be initialed and dated. All caregivers and ISP team need to be informed of the changes.

Fatal Four Protocols: Mandatory protocol forms are required for the "Fatal Four" risks in all 24-hour residential settings and must be used in accordance with the Risk Tracking Record.

General Protocol Form. When individuals have health risks other than the Fatal Four, the team may elect to develop a protocol around each risk.; they will need to use the format given in the New ISP Manual to ensure that all elements of the protocols are covered. Elements of a protocol are as follows:

- Brief description of the problem/contributing factors
- Preventative measures in use
- Signs and symptoms to look for
- Interventions
- When to call 911

Pain Protocol: Evaluating pain is difficult when a person can't articulate if, how, when and where they hurt. Caregivers are left to interpret behaviors, gestures, vocalizations and facial expressions as indicators of pain. If there is frequent caregiver turnover, no one may know the person well enough to establish how the person

communicates pain and discomfort. Even if a person can communicate with words, they may still not be able to communicate the nuances of their pain in a productive method. The following example of a pain protocol lists some generalized pain indicators, but also leaves room for the nurse and caregivers to list signs and symptoms that are unique to the individual. This protocol is useful for the home and employment program, but should also accompany the person to other settings, such as a hospital or nursing care facility where he/she will be cared for by unfamiliar caregivers.

Common Health Problems for DD Individuals

There are four major health issues that are more common in people with developmental disabilities than in the general population that can lead to severe morbidity and even death. They are frequently referred to as the “fatal four” risks: aspiration, dehydration, constipation, and epileptic seizures.

Aspiration, dehydration and constipation may be insidious conditions that often go unrecognized. Many of the symptoms are subtle and persons with disabilities may not be able to express their discomfort or give indications that they are not feeling well.

If a person has epileptic seizures, it is the suddenness and the unpredictability of this disorder that places the person most at risk. Injury, aspiration, drowning accidents and seizures that continue without stopping may cause hospitalizations and/or even death.

For all of the “fatal four” risk, astuteness of the caregivers and careful monitoring can greatly minimize these hazards and ensure timely interventions should they occur. The following information will help nurses identify individuals with these risks and provide guidance on assessments, plans of care and protocols.

Aspiration

Aspiration is defined as the inhalation of food, fluid, saliva, medication or other foreign material into the trachea and lungs. Any material can be aspirated on the way to the stomach or as stomach contents are refluxed back into the throat. The following information will help identify risk factors and interventions that may be unique to persons with developmental disabilities.

FACTORS THAT PLACE INDIVIDUALS AT RISK FOR ASPIRATION:

- Being fed by others
- Inadequately trained caregivers assisting with eating/drinking
- Weak or absent coughing/gagging reflexes, commonly seen in persons who have cerebral palsy or muscular dystrophy
- Poor chewing or swallowing skills
- Gastroesophageal reflux disease (GERD, GER) which can cause aspiration of stomach contents
- Food stuffing, rapid eating/drinking and pooling of food in the mouth
- Inappropriate fluid consistency and/or food textures
- Medication side effects that cause drowsiness and/or relax muscles causing delayed swallowing and suppression of gag and cough reflexes
- Impaired mobility that may leave individuals unable to sit upright while eating
- Epileptic seizures that may occur during oral intake or failure to position a person on their side after a seizure, allowing oral secretions to enter the airway.

REVIEW THE HEALTH HISTORY FOR ASPIRATION RISKS

- A diagnosis of risk for aspiration or past episodes of aspiration
- A diagnosis, such as cerebral palsy, muscular dystrophy, epilepsy, GERD, dysphagia or hiatal hernia
- History of aspiration pneumonia
- Needing to be fed by others

- History of choking, coughing, gagging while eating
- Needs modified food texture and fluid consistency
- Eating/swallowing evaluations and laboratory tests (barium swallow, pH study, etc) that indicates dysphagia
- Has unexplained weight loss or chronic dehydration
- Takes medications that may decrease voluntary muscle coordination or cause drowsiness
- Has unsafe eating and drinking practices, such as eating/drinking rapidly and food stuffing
- Has chronic chest congestion, frequent pneumonia, moist respirations, persistent cough or chronically uses cough/asthma medications

MEALTIME BEHAVIORS THAT MAY INDICATE ASPIRATION

- Eating slowly
- Fear or reluctance to eat
- Coughing or choking during meals
- Refusing foods and/or fluids
- Food and fluid falling out the person's mouth
- Eating in odd or unusual positions, such as throwing head back when swallowing or swallowing large amounts of food rapidly
- Refusing to eat except from a "favorite caregiver."

SIGNS AND SYMPTOMS THAT MAY INDICATE ASPRIATION RISK

- Gagging/choking during meals
- Persistent coughing during or after meals
- Irregular breathing, turning blue, moist respirations, wheezing or rapid respirations
- Food or fluid falling out of the person's mouth or drooling
- Intermittent fevers
- Chronic dehydration
- Unexplained weight loss
- Vomiting, regurgitation, rumination and/or odor of vomit or formula after meals

ASPIRATION INTERVENTIONS

- Call 911 if the person stops breathing and start CPR
- Stop feeding/eating immediately (may restart meal if feeding/dining instructions, supervisor or health care professional gives permission)
- Keep person in an upright position and encourage coughing
- If in doubt on what to do, call the health care professional or 911

GUIDELINES ON HOW TO PREVENT OR MINIMIZE THE RISK OF ASPIRATION

- Obtain a consultation by a swallowing specialist if symptoms occur
- Change diet consistency, texture or temperature (need a physician's order)
- Slow the pace of eating and decrease the size of the bites
- Position to enhance swallowing during meal times
- Keep in an upright position after meals for 45 minutes or as ordered
- Elevate the head of the bed 30 to 45 degrees
- Avoid food/fluids 2-3 hours before bedtime
- Consider the use of medications to promote stomach emptying, reduce reflux and acidity
- Write an aspiration protocol and written instructions on how the person is to eat or be fed and provide caregiver training. Cover the following: a) the assistance level needed, b) correct positioning for all oral intake and tooth brushing, c) eating/feeding equipment needed, d) physical and verbal cueing needed, e) location of meals. Some individuals may need to eat alone as they become distracted when eating with their peers, and f) recognition of aspiration symptoms, what to do about if noted and who to notify

ASPIRATION RISKS AND FEEDING TUBES

Many individuals with developmental disabilities have permanent gastrostomy feeding tubes (jejunostomy tubes). Have a feeding tube does not eliminate the risk of aspiration. Stomach contents can still enter the airway via regurgitation or oral secretions can be aspirated if the person has dysphagia. Occasionally anti reflux surgery will be performed to tighten the lower esophageal sphincter. Having this surgery will not conclusively eliminate the risk of aspiration, but should lessen the risk. Some standard aspiration precautions are:

- Administering tube feedings in an upright sitting position and keep upright for at least 45 minutes after
- If the person must be fed in bed, keep the head of bed at a 45 degree angle while feeding and for 45 minutes to an hour after
- Don't overfill the stomach
- Formula given at room temperature is better tolerated
- Don't feed too rapidly; feedings should be administered over at least 30 minutes or as ordered

After receiving a feeding tube, some individuals continue to eat small portions of their favorite foods orally. For these individuals, complete elimination of oral intake would take away a very valued activity-eating. To allow someone to eat after a feeding tube is placed is a difficult decision as even small infrequent amounts of food taken orally could be aspirated. The pros and cons of this decision should be discussed thoroughly by the team with good documentation on why the team reached its decision. If the team feels that the person should have some oral intake, guidelines should be written about what foods, how and when the person can be fed.

Constipation

Constipation is when an individual has difficulty passing stool; the stools are hard, dry and often look like marbles. The frequency of bowel movements varies greatly from person to person. Bowel movements are considered normal as long as the feces is soft, normal sized and is passed easily out of the bowel.

FACTORS THAT PLACE INDIVIDUALS AT RISK FOR CONSTIPATION

- Neuromuscular degenerative disorders that impair the central nervous system's response for the need to eliminate
- Spinal cord injuries or birth defects that affect neural responses needed for elimination such as spina bifida
- Individuals with muscle weakness who lack the strength and tone needed for adequate bowel function
- Diets that do not contain enough fiber and fluids
- Poor swallowing skills with aspiration risk making it difficult to eat and drink adequate amounts of fiber and fluid
- Inadequate or inconvenient access to the bathroom
- Immobility and poor body alignment that does not allow for optimum positioning for bowel elimination
- Poor toileting habits and routines or lack of privacy and time for toileting
- Medications that slow down gastric motility or draw too much fluid from the GI tract
- Hemorrhoids or other conditions that make bowel elimination painful
- History of frequent bowel stimulant use leading to decreased bowel reactivity
- Repression of the urge to defecate due to psychiatric issues

REVIEW OF HEALTH HISTORY FOR RISK OF CONSTIPATION

- Has a current or previous diagnosis of constipation
- Has a routine order for bowel medications and/or treatments
- Use PRN bowel medications

- Hospitalizations or outpatient treatments for constipation (bowel impaction, obstruction or obstipation)
- Takes medications that affect the body's hydration status or have constipating side effects
- Diet orders to increase dietary fiber (prunes, bran, psyllium etc) without adequate fluid intake
- Individual has a constipation protocol
- Caregiver's documentation indicates that the individual complains of stomach discomfort, strains with elimination, has abdominal distention, makes frequent trips to the bathroom or engages in rectal digging
- Bowel record shows that the individual is passing hard feces or bowel movements more than 2-3 days apart
- Recent decrease or stopping of routine bowel medications

SIGNS AND SYMPTOMS OF CONSTIPATION

- Spending a lot of time on the toilet
- Straining and grunting while passing stool
- Refusing to eat or drink
- Hard, small, dry feces
- Hard, protruding abdomen (usually an emergency)
- Vomiting digested food that smells like feces (is an emergency)
- Bloating and complaints of stomach discomfort

CONSTIPATION INTERVENTIONS

- Dietitian consultation regarding the type of food, texture, fiber content and fluid requirements to enhance elimination
- Implement an individual constipation protocol and train caregivers: a) how to identify constipation symptoms, what to do if they occur and who to notify, b) fluid requirements, c) when to give PRN bowel medications and how to document the results, e) when to toilet the individual, f) how and where to document bowel movements, g) to report observations and/or data to the health care professional routinely and as needed

GUIDELINES ON HOW TO PREVENT OR MINIMIZE CONSTIPATION

- Encourage physical activity to increase muscle strength and tone
- A positioning schedule for non-mobile individuals with time in an upright position. May need a physical therapist's advise
- Review of medication for side effects of constipation
- Establish toileting routines and schedule, for example: a) drinking a warm beverage first thing in the morning, b) teaching the person to take slow, deep breaths to increase abdominal pressure during toileting, c) teaching the person to respond to the natural urge to defecate, d) placing feet on a small step stool while sitting on the toilet, e) providing enough time and privacy for toileting

OBSERVATIONS THAT SHOULD PROMPT CONCERN

- No bowel movement for more than three days
- Last two bowel movements were hard and/or small
- In the last three days, only small bowel movements recorded

OBSERVATIONS THAT SHOULD PROMPT A REVIEW BY A HEALTH PROFESSIONAL

- Abdomen firm to touch and/or looks distended and bloated
- Complaints of stomach pain
- Vomiting without any fever or flu-like symptoms and/or vomiting material that smells like fecal material (call 911)
- Runny liquid stools after several days of passing small hard stools, small liquid stools or no bowel movements

Dehydration

Dehydration occurs when an individual does not drink enough fluids. Fluids are needed for temperature control, chemical balance and for cells to make energy and get rid of waste products. Dehydration occurs when the body loses more fluid than is replaced.

FACOTRS THAT PLACE INDIVIDUALS AT RISK FOR DEHYDRATION

- Unable to access fluids without assistance
- Needing assistance with drinking
- Dysphagia with coughing and choking during meals
- Food, fluid and saliva falling out of a person's mouth
- Frequently refusing food and fluids
- Suppression of thirst mechanism that results in the inability to recognize thirst
- Unable to effectively communicate thirst to caregivers
- Medical conditions where fluid loss can potentially cause dehydration, such as kidney disease or diabetes
- Conditions where the individual loses body fluids, such as drooling, diarrhea, sweating and vomiting
- Taking medications that affect body fluid balance, such as diuretics

REVIEW OF HEALTH HISTORY FOR RISK OF DEHYDRATION

- Physician has written a diagnosis of dehydration
- Physician has written an order for a minimum amount of fluid each day
- Has required intravenous fluids for dehydration either as an outpatient treatment or when in the hospital
- Takes a medication that affects body fluid balance, such as a diuretic
- Has a history of difficulty with drinking fluids, such as refusal or spillage
- Cannot independently access fluids or communicate thirst
- Has a protocol for dehydration

- Weight record reflects rapid weight loss
- History of frequent vomiting/diarrhea
- Has any type of stoma

SIGNS AND SYMPTOMS THAT AN INDIVIDUAL MAY BE DEHYDRATED

- Dry skin and poor skin elasticity
- Extreme thirst
- Dry, sticky mucous
- Lethargy and decreased alertness
- Fever
- Increased heart rate and decreased blood pressure
- Decreased urination, dark colored urine and concentrated urine smell

DEHYDRATION INTERVENTIONS

- Offer fluid intake if the individual is alert and able to drink safely
- If unable to take fluid safely, call health care professional for administration of intravenous fluids.

GUIDELINES FOR DEHYDRATION PREVENTION

- Individuals should be encouraged to drink 8-10 glasses of fluid/day: persons who weigh more must drink more; persons who weigh less need less
- If a person is reluctant to drink fluids, offer foods high in fluid content, such as gelatin, watermelon, puddings, yogurt or ice cream
- Persons who are very active, work hard, have a fever or perspire heavily need more fluids
- Persons who have cardiac or kidney disease may need less fluid
- A person with dysphagia needs a swallowing evaluation by a health care professional
- Implement a dehydration protocol and provide caregiver training including; a) having clear instructions regarding fluid requirements, b) listing acceptable minimal amount of fluid intake/day, c) consider the need for monitoring of intake and

output, d) list of signs and symptoms of dehydration, what to do if seen and who to notify

Seizure Disorder (Epilepsy)

Epilepsy is a disorder of the brain that is characterized by recurring seizures. Individuals with developmental disabilities are more likely to have epilepsy because of an underlying brain dysfunction. Head injuries, brain tumors, and brain congenital abnormalities are some causes of epilepsy. The clinical expression of an epileptic seizure varies according to where it starts in the brain.

FACTORS THAT PLACE INDIVIDUALS AT RISK FOR EPILEPSY

- Prenatal and postnatal brain injury, such as trauma, anoxia, infection
- Congenital brain malformations
- Brain tumors, clots, hemorrhage, aneurysms
- Traumatic brain injuries

REVIEW OF HEALTH HISTORY FOR RISK OF EPILEPSY

- Has a diagnosis of seizures, seizure disorder or epilepsy
- Has a history of a seizure(s) within the last five years
- Has an epilepsy protocol
- Takes antiepileptic medications for epilepsy or has had other treatments, such as a vagal nerve stimulator or ketogenic diet

GUIDELINES FOR SEIZURE PREVENTION

- Give antiepileptic medication on time as prescribed. Review the missed medication protocol
- Promote good relationships with health care professionals/specialists by providing accurate documentation and record keeping, keep appointments and be on time
- Encourage the person to live a moderate life style by encouraging adequate sleep, low stress, good nutrition and discourage alcohol intake

IMMEDIATE INTERVENTIONS WHEN AN INDIVIDUAL HAS A SEIZURE

- Stay with the person and guide gently away from or prevent access to dangerous areas
- Do not place anything in the person's mouth
- Move objects away from the person to prevent injury
- Only move the person if in an unsafe areas such as a roadway or stairwell
- If in water, keep the person's head above the water
- Don't restrain the person's movements
- Pad under the person's head, arms and legs
- Keep track of how long the seizure lasts

AFTER THE SEIZURE

- Turn the individual on their side when relaxed
- Loosen clothing
- Check for injuries and treat appropriately
- Document the seizure on a seizure calendar or record
- Allow the person sufficient time to recover before returning to activities

CALL 911 IF

- Two or more seizures occur without full recovery of responsiveness between seizures (unless the seizure protocol directs otherwise)
- When breathing does not resume after a seizure start rescue breathing
- When this is the person's first seizure
- When the person may have aspirated (seizure occurs during eating, bathing, swimming, etc)
- When a seizure lasts for more than 5 minutes (unless the seizure protocol directs otherwise)
- When the person cannot be aroused two hours after the seizure (unless their protocol directs otherwise)

- When an injury has occurred that needs medical attention (follow your agency policy)

GENERAL INTERVENTIONS

- Keep an accurate description of seizures and track all seizures in a consistent manner
- Monitor for medication side effects
- Keep the environment safe: a) water safety precautions, such as 1:1 continual observation in pool/tub, wearing a lifejacket, using a shower only or no tub baths. Precautions must be considered when bathing/swimming if there has been a seizure in the past 12 months or antiepileptic medications have been changed within the last 6 months.
- Monitor for complications with safety devices, such as wearing a helmet, elbow and/or kneepads and in keeping the devices in good repair
- Consider community safety precautions, such as 1:1 observation in the community or bicycle safety
- Individualized seizure protocol with caregiver trainings: a) description of the person's normal seizure pattern(s), b) safety interventions, c) degree of safety precautions in the home and community, d) caregiver instruction if person has a seizure and who to notify, when to call 911 and the administration of PRN medications if ordered

OBSERVATIONS THAT SHOULD PROMPT A REVIEW BY A HEALTH PROFESSIONAL

- Increase in the number and/or intensity of the seizures
- New episodes or attacks that look like epileptic seizures
- Change in the description of the seizures
- Multiple seizure descriptions or poorly defined seizure descriptions
- Repeated minor injuries or suspected aspirations as a result of seizures
- Increased lethargy or cognitive decline

- Illness with vomiting/dehydration and/or not able to take medications
- Repeated refusal of medications and use of protective devices