



Caring for People with Medical Needs

A Resource for Developing Care Guides

For agencies supporting people with intellectual disability/autism (ID/A)

Table of Contents

Introduction _____	4
How to Use This Resource _____	5
Option 1 _____	5
Option 2 _____	6
Points of Consideration for Agencies Developing Care Guides _____	8
Resources for Project Management Strategies _____	9
Catheters: Urinary, Biliary, and Nephrostomy _____	10
Seek Physician Guidance and Orders _____	10
Points of Consideration for Caring for People with Catheters _____	11
Specific Considerations for Catheters _____	11
Daily Care Considerations _____	13
Documentation _____	13
Education _____	13
Resources for Care Guide Development and Additional Information _____	14
Diabetes Management _____	15
Suggested Points of Discussion for People with Diabetes at All Health Evaluations	15
Seek Physician Guidance and Orders _____	15
Choosing a Glucometer _____	16
Points of Consideration for Caring for People with Diabetes _____	16
Specific Considerations for Diabetes Management _____	17
Daily Care Considerations _____	17
Documentation _____	18
Education _____	18
Resources for Care Guides and Further Information _____	19
Feeding Tubes _____	20
Types of Feeding Tubes _____	20
Use of the Feeding Tube _____	20
Seek Physician Guidance and Orders _____	21
Points of Consideration for Caring for People with Feeding Tubes _____	22
Specific Considerations for Feeding Tubes _____	22
Daily Care Considerations _____	24
Documentation _____	25

Education	25
Resources for Care Guides and Further Information	26
Ostomies: Colostomy, Ileostomy, Urostomy	27
Seek Physician Guidance and Orders	27
Points of Consideration for Caring for People with Ostomies	28
Specific Considerations for Ostomies	28
Daily Care Considerations	30
Documentation	30
Education	30
Resources for Care Guides and Further Information	31
Respiratory Therapies	32
Seek Physician Guidance and Orders	32
Points of Consideration for Caring for People with Respiratory Therapies	333
Specific Considerations for Respiratory Therapies	333
Daily Care Considerations	366
Documentation	366
Education	366
Resources for Written Documents and Further Information	377
Tracheostomy	388
Seek Physician Guidance and Orders	388
Points of Consideration for Caring for People with Tracheostomies	399
Specific Considerations for Tracheostomy	399
Daily Care Considerations	41
Documentation	422
Education	422
Resources for Written Documents and Further Information	433
Template for Care Guide Development	444
Sample Template for Care of a Person with a Laceration (Cut)	455

Introduction

Caring for people with chronic health conditions in home settings is becoming more commonplace. As a result, agencies supporting people with intellectual disability/autism (ID/A) in residential settings may be asked to care for people with complex medical needs. The care required may be unfamiliar to them and may require additional training and skills to maintain the person's health and safety. Such care needs may include care of a catheter, tracheostomy, or feeding tube.

Agencies may wish to develop written care guides that provide an organized, specific, and consistent way to deliver safe care for the person with medical needs. Care guides are useful because they can:

- Provide guidance to employees regarding the person's care
- Communicate agency expectations regarding the person's care
- Provide direction on how to manage concerns that may arise regarding the person's care or condition
- Specify training and competency requirements related to the person's care

The KEPRO Southwestern PA Healthcare Quality Unit is pleased to provide, *Caring for People with Medical Needs: A Resource for Developing Care Guides*, for agency use and reference. This resource is intended to prompt agencies to identify care requirements for people with medical needs, based on accepted care standards and health care provider input, and to provide reputable resources that may be consulted for further information on the topic. It is hoped that once care requirements are identified, provider agencies would develop care guides medical needs, which provide direction to caregivers for how to support the person, with a focus on maintaining health and safety.

Care guides, developed by provider agencies regarding medical needs, may be general or person specific. Agencies may wish to consider including person specific guidelines into the individual's Individualized Support Plan (ISP).

Disclaimer: The HCQU cannot write, review, or approve care guides, but can act as a resource to agencies during their development. Resources provided by the HCQU will only include information specific to people with ID/A and reputable sources of information for specific care needs.



How to Use This Resource

Medical needs covered in this resource are:

- Catheters
- Diabetes Management
- Feeding Tubes
- Ostomies
- Respiratory Therapy
- Tracheostomy

The HCQU envisions that agencies may use this resource in TWO ways:

Option 1

A reference tool for agency personnel to address individualized and person specific care needs with healthcare personnel caring for the person.

Healthcare personnel may include physicians, nurses, educators from product and equipment companies (i.e., an educator from the company that manufactures colostomy bags), dietitians, pharmacists, and therapists, both in medical and home settings. In many instances, physicians don't write orders for every aspect related to care, but rely upon other health care personnel to know what to do and to communicate that information to

the patient. For example, physicians would not usually write an order for how often to run quality testing on a glucometer. They would expect a diabetes educator or nurse to read the recommendations for quality testing of the machine from the manufacturer and communicate that information to the patient. Another example, physicians would not usually write orders for how often to change the tubing on a tube feeding or oxygen administration set. They would expect nurses and educators to provide the patient with this information.

According to *Understanding the Office of Developmental Programs (ODP) in Pennsylvania: Intellectual Disability and Autism Services*, people receiving funding from the Consolidated Waiver must have their assessed needs met. The supports provided to meet the needs should be individualized and specific to the person. Source: The Training Partnership, The Gold Book retrieved from <http://pawaitinglistcampaign.org/wp-content/uploads/2015/11/goldbook2013.pdf>.

It is suggested that caregivers take the entire section pertaining to the individual's medical need from this resource to the physician and ask him or her to address the items under the *Seek Physician Guidance and Orders* section, and to answer the questions in the sections that follow.

If the physician is unable to answer a question because the responsibility for that item lies with another healthcare provider, it is suggested that agencies show the list of questions to other healthcare providers involved in the person's care for their input and direction.

Agencies can then use all of the information gathered by having healthcare personnel address items for consideration outlined in this resource to write a person specific guideline for the person's care.

Agencies may wish to contact the person's Supports Coordinator (SC) to incorporate the person specific guidelines for care into the person's Individual Support Plan (ISP).

Option 2

A resource for developing generalized care guides for caregiver direction and reference regarding health situations listed above. Suggested steps to follow to do this are:

1. Locate the medical concern of interest
 - a. Available topics are listed alphabetically in this resource
 - Catheters
 - Diabetes Management
 - Feeding Tubes

- Ostomies
 - Respiratory Therapy
 - Tracheostomy
2. Read through the information provided. A brief explanation of medical needs is provided, along with points for consideration when developing the guides. The points for consideration are in question format.
 3. Use the resource list provided at the end of each section to learn of accepted practices and sound advice from reputable sources related to the topic.
 4. Highlight the considerations that are important for your agency. In doing this, it may be a good idea to consider existing agency policy and procedure, regulatory guidelines, and accepted standards of care for the medical need.
 5. Use the answers to the identified points of consideration to provide the foundation for developing the care guides to address the medical need.
 6. Healthcare providers, such as agency nurses, doctors, or other licensed personnel affiliated with the agency may be a source of reputable information about the medical need.

Disclaimer: The resources used to compile the information included in each section are listed at the end of each section. These are also recommended resources for provider agencies to use when developing care guides.



Points of Consideration for Agencies Developing Care Guides

- Agencies may be faced with the need for care guides on an urgent basis, such as after a person has been in the hospital. It is suggested that in these instances agencies follow Option 1 of How to Use this Resource, on page 7. Option 1 will assist provider agencies to develop individualized and person specific care guides for a standardized and consistent approach to the person's care in a timely fashion.
- In an effort to be proactive, rather than reactive, agencies may wish to adopt a timeline for following Option 2 of How to Use this Resource, on page 8.
- Even when an agency has a generalized care guide for a health concern, it is suggested that a personalized care guide be developed for each person supported by the agency with that health concern. Remember that an individualized plan drives and directs the specific care measures for the person.

- Decide when to write the documents, if following Option 2. General care guides do not have to be developed all at once. It may be helpful to consider the likelihood of a person in your support to have a medical need that is included in this resource to determine the priority for developing the care guides. The process of developing care guides for people with medical concerns can take some time and effort. Consider the use of project management strategies throughout the process. Such strategies may include a committee composed of various levels of employees throughout the agency, a sub-committee dedicated to research related to the complex medical concern, a sub-committee dedicated to writing the document, development of an outline with due dates for the project, and identification of the strengths of agency personnel to decide who is best suited to perform specific parts of the process. For example, licensed clinical personnel may best understand medical words and procedures mentioned in the resources; administrative personnel may best understand Office of Developmental Programs (ODP) requirements and regulations; direct support caregivers may best understand the most effective way to provide the care.
- Once the care guides are written, they can be used to train caregivers in the care of the person. This is true of documents written from both Option 1 and Option 2. Suggestions around the training process are to consider how to initially train caregivers and how and when they will be considered competent to care for the individual; consider how often they should demonstrate competency and how that will be done; consider how substitute caregivers at other locations such as a Day Program will be instructed in the care of the person. Agencies may also wish to consider training methods, such as instructor led, self- learning, and return demonstration.
- Agencies may want to consider naming the care guides in accordance with their purpose, keeping in mind that the final product should provide information related to the health and safety of the person with the specified complex medical need.

Resources for Project Management Strategies

Hardy-Vallee,B. (2012, February 21). *How to Run a Successful Project*. Retrieved February 24, 2023, from Gallup Business Journal, <https://news.gallup.com/businessjournal/152756/run-successful-project.aspx>

Catheters: Urinary, Biliary, and Nephrostomy

A catheter is a thin, sterile tube used to drain fluid from a body part. Types of catheters commonly used at home are urinary (in the bladder), biliary (in the common bile duct where the liver and gallbladder are joined), and nephrostomy (in the kidney). Biliary and nephrostomy tubes are inserted by a doctor and are left in place until the doctor removes them. They may require dressing changes and flushing at home.

Urinary catheters can be used several times a day, (intermittent catheterization) or left in place. A urinary catheter that is left in place for a period of time is known as a Foley catheter. People who require long term catheter use due to inability to empty the bladder may get a catheter inserted through a small hole in the abdomen, which is called a suprapubic catheter. A balloon on the end of a Foley or suprapubic catheter keeps it in place. Accidental removal of the catheter without deflating the balloon can cause injury to the person.

Indwelling catheters, including biliary and nephrostomy catheters, are connected to drainage bags. Many people with a urinary catheter use a large drainage bag at night, and a smaller bag that attaches to the leg, during the day. Potential risks associated with a catheter include blockage and infection.

Seek Physician Guidance and Orders

Care and management of the catheter is based on agency policies, best practice standards, and physician's orders. It is suggested that caregivers discuss the following with the physician:

- Catheter type
- Foley
- Suprapubic
- Intermittent catheterization
- Biliary
- Nephrostomy
- Size of catheter
- Type of catheter (if Foley, curved tip or straight tip)
- For Foley or suprapubic catheters, amount of sterile water needed for the balloon
- Frequency of catheterization, if intermittent
- Frequency of catheter change if indwelling
- Recommendations for reporting the drainage or output from the catheter
- Catheter care procedure
- The need to flush the catheter and orders for flushing, including what solution to use
- Care of the catheter insertion site for biliary, nephrostomy and suprapubic catheters
- How to decrease the risk for infection

- Recommended daily fluid intake
- What to do if the catheter cannot be flushed (if ordered) or there is no drainage from the catheter
- What to do if the drainage bag comes apart from the catheter
- What to do if the catheter comes out
- When to contact the doctor

Note: Some answers to these questions may be person specific and can be used to develop individualized care guides related to the person's care.

Points of Consideration for Caring for People with Catheters

1. Scope of Care Guide

- Who and what does this care guide cover?
- Is this a generalized document?
- Is this a person specific document?
- How will information be communicated to other programs supporting the person?

2. Supplies Needed

- What supplies are needed?
- What is the procedure for ordering the supplies?
- Who will be responsible for ordering supplies?
- What company will provide supplies?
- How many of each item should be available?
- If the person attends a day program, what supplies are needed at that site, and who is responsible?
- What supplies are needed when the person travels?

Specific Considerations for Catheters

1. Catheterization

- Who will be permitted to perform intermittent catheterization?
- How will Foley or suprapubic catheters be changed?

2. Urinary catheter skin care

- Is a doctor's order needed for specific care procedures?
- What is the procedure for cleaning around the insertion site?
- How often should the area be cleaned?
- What products should be used or avoided when performing catheter care?

- e. Who will be responsible for skin care around the insertion site?
- f. What changes in skin condition should be reported to the physician?

3. Urinary Catheter, Biliary, or Nephrostomy Tube Bags

- a. What is the procedure to change catheter bags?
- b. Who will be responsible for changing the bag?
- c. When should the catheter bag be changed?
- d. When should the catheter bag be emptied?
- e. Should the amount of urine in the bag be recorded?
- f. When should the catheter bag be disposed of?
- g. Will catheter bags be cleaned and reused? If so, how should the bags be cleaned?

4. Flushing of Foley Catheter

- a. Who is permitted to flush the Foley catheter?
- b. When should the catheter be flushed?
- c. Are there specific situations that would require flushing?
- d. What is the exact procedure for flushing?
- e. How often should the catheter be flushed?
- f. Is flushing permitted on an as needed basis for a clogged catheter?

5. Flushing of Biliary or Nephrostomy Tube

- a. Who is permitted to flush the biliary or nephrostomy tube?
- b. When should these tubes be flushed?
- c. Are there specific situations that would require flushing?
- d. What is the exact procedure for flushing?
- e. How often should the catheter be flushed?
- f. Is flushing permitted on an as needed basis for a clogged catheter?

6. Troubleshooting Catheters

- a. What should be done if there is decreased output from the catheter?
- b. What should be done if the bag comes apart from the catheter?
- c. What should be done if the catheter comes out?
- d. When should caregivers call EMS?
- e. When should caregivers call the doctor?

Daily Care Considerations

1. Should the person take a bath or shower?
2. What type of clothing should be worn to accommodate tubing and catheter bag?
3. Should a different drainage bag be used at night?
4. Should intake and output be recorded?

Documentation

1. What should be documented and how often is documentation required?
2. How and where should caregivers document?
3. What types of care of the catheter were performed?
4. Is the catheter flushed?
5. What is the person's intake and output?
6. What is the output of the catheter?
7. What are the characteristics of the drainage from the catheter?
8. Were there any difficulties with the catheter?
9. What was the person's response to care?

Education

1. How will caregivers be educated regarding caring for the person with a catheter?
2. How will the education be individualized to meet the person's specific care needs?
3. Who will provide the education?
4. Will a "train the trainer" process be used?
5. How will caregivers demonstrate competency? How often?
6. How will caregivers be educated prior to the person's discharge from a hospital or nursing home?
7. How will non-residential caregivers (i.e. Day Program caregivers) be educated?
8. Who is responsible for educating the person's family members for home visits?
9. Where is the education documentation located?
10. What education will be provided to the person with the medical concern?

Resources for Care Guide Development and Additional Information

Cincinnati Children's Hospital. (2021, July). *Nephrostomy Tube Care*. Retrieved February 24, 2023, from <http://www.cincinnatichildrens.org/health/n/nephrostomy/>

Medline Plus. (2022, May 4). *Biliary Duct Obstruction*. Retrieved February 24, 2023, from <http://www.nlm.nih.gov/medlineplus/ency/article/000263.htm>

UVA Health. (n.d.). *Biliary Drainage*. Retrieved February 24, 2023, from <https://uvahealth.com/services/imaging/biliary-drainage>



Diabetes Management

Diabetes is a condition characterized by having too much sugar in the blood. Complications from diabetes are directly related to blood sugar levels over time and can affect all body systems and organs. People with chronic health conditions and diabetes may have increased care needs in multiple areas. For this reason, the Office of Developmental Programs recommends diabetes management at each health evaluation with any doctor and has included it in the Individual Support Plan (ISP).

Suggested Points of Discussion for People with Diabetes at All Health Evaluations

1. Effect of diabetes on the person's general health/health condition
2. Suggestions for blood glucose levels
3. Recommended medications or treatments for current health concern because of diabetes

Seek Physician Guidance and Orders

Most often management of the diabetes itself is coordinated by the person's PCP or by an endocrinologist. Care and management of the diabetes is based on agency policies, best practice standards, and physician's orders. It is suggested that caregivers discuss the following with the physician:

- Type of diabetes
- Target blood sugar levels
- Target weight, blood pressure, and cholesterol levels
- Recommended diet
- Recommended activity level
- The expected action, onset, and side effects of prescribed medications
- Recommended blood sugar testing schedule
- Recommended action for high and low blood sugar readings
- Frequency and preferred method of sharing blood sugar readings with physician
- Recommended tests and how often they are needed
- Recommended treatments or therapies to manage other health conditions that can worsen diabetes
- Need for and frequency of referrals to other specialists
- Referral to dietician
- Recommended educational resources
- Treatment for sick days
- When to call the physician
- When to seek emergency care

Note: Some answers to these questions may be person specific and can be used to develop individualized care guides related to the person's care.

Choosing a Glucometer

A glucose meter or glucometer is used to self-monitor blood glucose. Self-monitoring of blood glucose is recommended for all people with diabetes, but especially for those who take insulin. The physician will determine how often the meter is used. There are many different types of meters. Points to consider when choosing a meter to test blood sugar at home are:

- Ease of use
- Amount of blood needed for each test
- Recommended puncture sites (some people may do better pricking an arm versus a fingertip)
- Recommended schedule and process for testing the meter
- Cost of supplies

Points of Consideration for Caring for People with Diabetes

1. Scope of Care Guide

- a. Who and what does this care guide cover?
- b. Is this a generalized document?

- c. Is this a person specific document?
- d. How will information be communicated to other programs supporting the person?

2. Supplies Needed

- a. What supplies are needed?
- b. Who will be responsible for ordering supplies?
- c. What company will provide supplies?
- d. How many of each needed item should be available?
- e. If the person attends a day program, what supplies are needed at that site and who is responsible?

Specific Considerations for Diabetes Management

1. Testing the Person's Blood Sugar

- a. What is the procedure for testing the blood sugar?
- b. What supplies are to be used to test the blood sugar?
- c. Who may perform the test?
- d. When should the test be performed?
- e. Where are blood sugar test results recorded?

2. Care of the Glucometer

- a. How and where will the meter and its supplies be stored?
- b. What care is required for the meter?
- c. How often should care of the meter be performed?
- d. Who is responsible to care for the meter?
- e. Who will perform the quality testing on the meter?
- f. When will the quality testing be performed?
- g. Where will the results of the quality testing be recorded?

3. Troubleshooting the Glucometer

- a. What should be done if the glucometer is not working properly?
- b. Where can a caregiver find the User Guide and phone number to the manufacturer for the glucometer?

Daily Care Considerations

1. How to handle sick days?

2. Should this person wear medical alert jewelry?
3. What are the recommendations for skin and nail care?
4. Are there any recommendations for daily foot care?
5. What should be done if the glucometer malfunctions or indicates high or low reading?
6. When to contact the physician?
7. When to seek emergency care?

Documentation

1. What should be documented and how often is documentation required?
2. How and where should caregivers document?
3. What care was provided for the person?
4. What were the blood sugar readings?
5. What types of glucose meter care are performed?
6. Was there communication with the doctor? If so, what was discussed?

Education

1. How will caregivers be educated about caring for the person with diabetes?
2. How will new caregivers be trained?
3. How will caregivers be educated on glucometer use?
4. Who will provide the education? Will a “train the trainer” process be used?
5. How will caregivers demonstrate competency? How often?
6. How will caregivers be educated prior to the person’s discharge from a hospital or nursing home?
7. How will non-residential caregivers (i.e. Day Program caregivers) be educated?
8. Who is responsible for educating the person’s family members for home visits?
9. Who is responsible to assure adherence to ODP regulations surrounding insulin use?
10. Where is the education documentation located?
11. What education will be provided to the person with the complex medical concern?

Resources for Care Guides and Further Information

American Diabetes Association. (n.d.). *Hyperglycemia (High Blood Glucose)*. Retrieved February 24 2023, from <https://www.diabetes.org/healthy-living/medication-treatments/blood-glucose-testing-and-control/hyperglycemia>

American Diabetes Association. (n.d.). *The Big Picture: Checking Your Blood Glucose*. Retrieved February 24, 2023, from <https://www.diabetes.org/healthy-living/medication-treatments/blood-glucose-testing-and-control/checking-your-blood-sugar>

Mayo Clinic. (2023, January 20). *Diabetes*. Retrieved February 24, 2023, from <https://www.mayoclinic.org/diseases-conditions/diabetes/symptoms-causes/syc-20371444>

Feeding Tubes

Feeding tubes are used to provide nutrition, fluids, and medication when these items cannot be taken by mouth. In cases of trauma or surgery to the mouth, the tubes may be temporary; in cases of difficulty swallowing and risk of aspiration with oral intake, the tubes are usually permanent. Readers of this guide will most likely be working with a permanent feeding tube.

There are many factors to consider for safe use of a feeding tube. Care guides for use of a feeding tube are designed to promote safety and minimize complications associated with a feeding tube, and they may be specific to the type of tube that is used. The presence of a feeding tube poses risks for the individual, including infection and aspiration; difficulty with the tube itself or the equipment used for the tube can occur, such as a clogged tube or a malfunctioning feeding pump. Care of the person with a feeding tube should recognize and plan for all aspects to maintain the person's health and safety.

Types of Feeding Tubes

There are a variety of feeding tubes. The tubes are named according to where they are inserted into the gastrointestinal (GI) tract.

Nasogastric tube or NG-tube is inserted into the nose and down to the stomach. This tube is used when nutritional support is required for a short period of time. It is unlikely that a person will return to a group home setting with this type of tube in place.

Gastrostomy tube or G-tube or PEG tube or G-J Tube or J-tube is a type of catheter which is surgically inserted into the skin of the abdomen. The opening formed through the skin is called a stoma. The stoma may require care to prevent infection. The end of the G-tube is in the stomach and the end of the J-tube is in the small intestine. Some of these tubes have more than one opening that can be used to give fluids or medications; some of these tubes have clamps or levers that need to be open when the tube is in use. It is important to know what type of tube the person has and exactly how to use it. The goal is to use the type of tube that will meet the person's nutritional needs while maintaining health and safety.

Use of the Feeding Tube

Fluids including water, to maintain hydration.

Enteral nutrition (nutrition delivered to the GI tract). This is in the form of a commercially prepared feeding formula. There are a variety of feeding formulas, all of which deliver varying amounts of calories and nutritional components. There are formulas

designed for specific medical concerns, such as diabetes and kidney disease. The formula may come in a can or in a large bottle. There are several ways to administer feedings through a tube, and each administration method has its own procedures and best practice standards. In most cases the person's nutritional needs are evaluated by a dietitian who recommends caloric and nutritional intake requirements; the physician chooses which administration method best meets the person's needs. The administration methods are:

- Continuous feedings via a feeding pump. In this administration method the person receives feedings at a continuous rate, 24 hours a day, using a machine designed to deliver the specified rate per hour.
- Intermittent feedings via a feeding pump. In this administration method the person receives a set amount of feeding over a short period, several times per day. The feeding pump is used to deliver the feeding.
- Intermittent bolus feedings via gravity. In this administration method the person receives a set amount of feeding formula delivered through a syringe via gravity several times per day.
- Night cycle schedule via feeding pump. In this administration method the person receives the feedings continuously during the night hours, such as from 6 PM to 8 AM.

Medications. Upon a physician's order, medications can be given through the feeding tube. Some medications cannot be given via feeding tube because they cannot be crushed, and proper medication preparation and administration techniques may vary, based on the medication's original form.

Seek Physician Guidance and Orders

Care and management of the feeding tube is based on agency policies, best practice standards, and physician's orders. It is suggested that caregivers discuss the following with the physician:

- Type and size of feeding tube
 - G-tube
 - PEG tube
 - G-J Tube
 - J-tube
- Schedule for planned replacement of the tube
- Administration of feedings via the tube
- Type of formula
- Amount of formula for each feeding
- Feeding administration method-continuous, intermittent via pump, intermittent via gravity, or night cycle
- Administration of medications via the tube
- Technique for administration
- Medications that should not be given via the feeding tube
- Administration of fluids via the tube

- Type of fluids to administer
- When to administer fluids
- Water bolus schedule
- Care of the insertion site
- Recommendations for safe care of the individual with a feeding tube
- When to hold medications, fluids, or feedings
- When to notify the physician
- When to seek emergency care

Note: Some answers to these questions may be person specific and can be used to develop individualized written documents related to the person's care.

Points of Consideration for Caring for People with Feeding Tubes

1. Scope of Care Guide

- a. Who and what does this care guide cover?
- b. Is this a generalized document?
- c. Is this a person specific document?
- d. How will information be communicated to other programs supporting the person?

2. Supplies Needed

- a. What supplies are needed? (The supplies required will vary, based on feeding administration method.)
- b. What is the procedure for ordering the supplies?
- c. Who will be responsible for ordering supplies?
- d. What company will provide supplies?
- e. How many of each item should be available?
- f. If the person attends a day program, what supplies are needed at that site, and who is responsible?
- g. What supplies are needed when the person travels?

Specific Considerations for Feeding Tubes

1. Use of the Feeding Tube

- a. Who will be permitted to administer feedings and fluids?
- b. Who will be permitted to administer medications?
- c. What is the exact technique and procedure to be followed for feeding, fluid, and medication administration via the feeding tube?
- d. Is it necessary to check for placement and residual feedings, and what is the procedure for this? When should the physician be notified related to findings from these procedures?

2. Stoma Site Care

- a. Is a doctor's order required for specific care procedures per agency policy?
- b. What is the procedure for cleaning around the insertion site?
- c. How often should the area be cleaned?
- d. What products should be used or avoided when performing stoma care?
- e. Who will be responsible for stoma care?
- f. What changes in the skin around the stoma should be reported to the physician?

3. Feeding Tube Set Up

- a. A feeding tube set up consists of the syringes, bottles or bags of formula and tubing used to deliver the prescribed treatments through the tube.
- b. What is the procedure to change the feeding tube set up?
- c. What specific items should be used to change the set up?
- d. Who will be responsible for changing the feeding tube set up?
- e. When should the feeding tube set up be changed?
- f. How should the syringe be maintained between uses?
- g. What should be done if the required equipment is unavailable?

4. Feeding Formula

- a. Temperature of formula for administration?
- b. Procedure for opening the can/storing leftover formula?
- c. Procedure for spiking the tube feeding bottle?
- d. Storage of unused formula?

5. Water for Flushing

- a. Temperature of the water?
- b. Type of water (tap or bottled)?
- c. How to measure water?
- d. When should water be administered?

6. Medications via Feeding Tube

- a. Is a physician's order required to administer medication via the feeding tube?
- b. Is a physician's order required to use a liquid medication versus a tablet or capsule form?
- c. Is a physician's order required to crush the medication?
- d. What is the procedure for crushing medication?
- e. What method is used to identify medications that can be given via feeding tube?
- f. What equipment is needed to administer medication via feeding tube?

- g. What is the technique and exact procedure for medication administration via the feeding tube?

7. Troubleshooting the Feeding Pump

- a. Who is permitted to troubleshoot the feeding pump?
- b. What should be done if the pump cannot be returned to working condition?
- c. What should be done if there is a power outage?

8. Troubleshooting the Feeding Tube

- a. What can be tried if the tube is clogged?
- b. Who can attempt to unclog the tube?
- c. What should be done if the tube cannot be unclogged?
- d. What should be done if the tube comes out?
- e. What should be done if the tube is leaking?
- f. When to call the physician?
- g. When to seek emergency care?

Daily Care Considerations

1. What should be done if the person appears to have trouble breathing?
2. What should be done regarding feedings, water, and medications via the tube if the person has signs of other illness?
3. What should be done if the person has a high residual (if checked)?
4. How should the person be positioned during and after feeding and medication administration?
5. What does mouth care mean for the person with a feeding tube and how often should it be administered?
6. Should the person take a bath or shower?
7. What type of clothing should be worn to accommodate the feeding tube?
8. What signs would indicate the person is not tolerating the feedings?
9. For the person using an abdominal binder
 - When should it be in place?
 - How many binders should be available?
 - How should the binder be cared for?
10. For the person requiring emergency care for the tube
 - What information should be taken to the hospital?

- What equipment should be taken to the hospital?

Documentation

1. What should be documented and how often is documentation required?
2. How and where should caregivers document?
3. What is the person's tolerance and response to tube feedings?
4. Was there side effects from the feedings, such as diarrhea or high residuals?
5. What was the condition of stoma?
6. What was the routine skin care or dressing change procedure?
7. Was there tube feeding, water, and, medication administration?
8. Was there difficulties with the feeding tube? If so, were there actions taken?
9. How was the abdominal binder used, if ordered?

Education

1. How will caregivers be educated about caring for the person with a feeding tube, including signs of distress and complications from the feedings?
2. How will new caregivers be trained?
3. How will the education provided be individualized for the person's type of tube and care needs?
4. Who will provide the education? Will a "train the trainer" process be used?
5. How will caregivers demonstrate competency? How often?
6. How will caregivers be educated prior to the person's discharge from a hospital or nursing home?
7. How will non-residential caregivers (i.e. Day Program caregivers) be educated?
8. Who is responsible for educating the person's family members for home visits?
9. Where is the education documentation located?
10. What education will be provided to the person with the complex medical concern?

Resources for Care Guides and Further Information

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Ostomies: Colostomy, Ileostomy, Urostomy

An ostomy is an opening that connects an internal organ to the outside of the body. The connection on the outside of the body from these internal organs is called a stoma. Ostomies are done as a surgical procedure to treat various diseases and they are named according to the organ involved. An ostomy can be temporary or permanent. Temporary ostomies may be created to give an organ time to heal; permanent ostomies may be required when the disease or its treatment interferes with normal function of the organ. The ostomies discussed in this section originate in either the intestinal system or the urinary system and end on the abdomen. Types of ostomies in these systems are

1. **Colostomy** - from the large intestine to the abdomen
2. **Ileostomy** - from the small intestine to the abdomen
3. **Urostomy** - from the bladder to the abdomen

The ostomy is a diversion for the normal function of the organ; once the opening is made to the abdominal wall, any material in that organ (feces or urine) will drain to the outside of the body through the stoma. The type and characteristics of the drainage will vary, depending upon the origin of the ostomy in the intestinal tract. The drainage is often referred to as the output from the ostomy.

The drainage from the stoma must be effectively contained to prevent skin irritation, odor, and soiling of clothing. A drainage collection system, often referred to as an ostomy appliance, is used to catch the drainage from the stoma. There are many different kinds of drainage collection systems; some have one piece and some have two pieces; all of them have a wafer that must be applied to the skin around the stoma. Common concerns include functionality of the ostomy, keeping the drainage collection system intact, and infection or irritation of the stoma and the skin surrounding it. The functionality of the ostomy can be affected by diet, exercise, and medication.

Seek Physician Guidance and Orders

Care and management of ostomies is based on agency policies, best practice standards, and physician's orders. It is suggested that caregivers discuss the following with the physician:

- Type of ostomy
 - Colostomy
 - Ileostomy
 - Urostomy
- Expected amount and characteristics of the output from the ostomy

- Expected characteristics of the stoma
- Care of the stoma
- Recommendations for frequency of ostomy appliance change
- Procedure for ostomy appliance change, including best position for the person during the procedure
- When to notify the physician
- When to seek emergency care

Note: Some answers to these questions may be person specific and can be used to develop individualized written documents related to the person's care.

Points of Consideration for Caring for People with Ostomies

1. Scope of Care Guide

- Who and what does this care guide cover?
- Is this a generalized document?
- Is this a person specific document?
- How will information be communicated to other programs supporting the person?

2. Supplies Needed

- What supplies are needed?
 - It may be a good idea to record the exact ostomy appliance name, manufacturer, and product number for future reference.
 - It may be a good idea to keep a pattern of the wafer part of the appliance to use to make future wafers.
- What is the procedure for ordering the supplies?
- Who will be responsible for ordering supplies?
- What company will provide supplies?
- How many of each item should be available?
- If the person attends a day program, what supplies are needed at that site, and who is responsible?
- What supplies are needed when the person travels?

Specific Considerations for Ostomies

1. Working with the Ostomy

- Who will be permitted to empty the ostomy bag?
- When should the ostomy bag be emptied?
- What is the exact technique and procedure to be followed for emptying the ostomy bag?

- d. Who will be permitted to change the ostomy appliance?
- e. When should the ostomy appliance be changed?
- f. What is the exact technique and procedure for changing the ostomy appliance?

2. Care of the Stoma and Surrounding Skin

- a. Is a doctor's order required for specific care procedures per agency policy?
- b. What is the procedure for care of the stoma and surrounding skin?
- c. How often should care of the stoma and surrounding skin be performed?
- d. What products should be used to care for the stoma and surrounding skin?
- e. Who will be responsible for this care?
- f. What changes in the stoma and/or the skin surrounding it should be reported to the physician?

3. Troubleshooting the Ostomy Function

- a. What changes indicate a problem with the function of the ostomy?
- b. What should be done if a problem with the function of the ostomy is identified?

4. Troubleshooting the Ostomy Appliance

- a. What should be done if the appliance is leaking?
- b. What should be done if the appliance is not securely attached?

Daily Care Considerations

1. How will the effects of certain foods on the output of the ostomy be noted?
2. What should be done if the person becomes ill?
3. Should the person take a bath or shower?
4. What type of clothing should be worn to accommodate the ostomy appliance?
5. For the person requiring emergency care for a problem with the ostomy
 - What information should be taken to the hospital?
 - What equipment should be taken to the hospital?

Documentation

1. What should be documented and how often is documentation required?
2. How and where should caregivers document?
3. What is the condition of stoma and the surrounding skin?
4. Was the ostomy appliance changed?
5. What type and amount of drainage came from the stoma?

Education

1. How will caregivers be educated about caring for the person with an ostomy?
2. How will new caregivers be trained?
3. How will the education provided be individualized for the person's type of ostomy and ostomy appliance?
4. Who will provide the education? Will a "train the trainer" process be used?
5. How will caregivers demonstrate competency? How often?
6. How will caregivers be educated prior to the person's discharge from a hospital or nursing home?
7. How will non-residential caregivers (i.e., Day Program caregivers) be educated?
8. Who is responsible for educating the person's family members for home visits?
9. Where is the education documentation located?
10. What education will be provided to the person with the complex medical concern?

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Respiratory Therapies

Various respiratory therapies can be used in the home setting. Some of the most common include delivery of oxygen and delivery of medication via nebulizer. The use of oxygen and breathing treatments at home may be temporary or permanent. If the individual is hospitalized, testing is usually performed prior to discharge to validate the need for these treatments in the home setting.

Additional respiratory equipment used in home settings include pulse oximeters and Bi-pap or C-pap machines. Pulse oximeters are used to detect oxygen levels and Bi-pap or C-pap is used to treat sleep apnea. All equipment used in the home setting requires maintenance and proper use for the person to receive the full benefit of the treatment.

Seek Physician Guidance and Orders

Care of the person receiving home respiratory therapy and the equipment used to deliver it is based on agency policies, best practice standards, manufacturer recommendations, and physician's orders. It is suggested that caregivers discuss the following with the physician: (All may not apply; ask the questions related to the therapy the person is receiving.)

- Specific type of therapy needed
 - Oxygen
 - Breathing treatments
 - Treatment for sleep apnea
 - Monitoring of oxygen levels
- Oxygen flow rate
- Oxygen delivery system-nasal cannula or face mask
- When to use the oxygen
- Specific medication to be used for breathing treatments
- When to administer breathing treatments
- Positioning of the person during breathing treatments
- Specific orders for the settings on the Bi-pap or C-pap machine
- When to use the Bi-pap or C-pap machine
- When to monitor oxygen levels
- Recommendations for safe care of the individual using respiratory therapies at home
- Giving extra oxygen or breathing treatments in an emergency situation
- What data to share on a regular basis with the doctor and how often to share it
- When to notify the physician
- When to seek emergency care

Note: Some answers to these questions may be person specific and can be used to develop individualized written documents related to the person's care.

Points of Consideration for Caring for People with Respiratory Therapies

1. Scope of Care Guide

- a. Who and what does this care guide cover?
 - Is this a generalized document?
 - Is this a person specific document?
- b. How will information be communicated to other programs supporting the person?

2. Supplies Needed

- a. What supplies are needed for
 - Oxygen therapy?
 - Breathing (nebulizer) treatments?
 - Bi-pap or C-pap?
 - Pulse ox?
- b. Who will be responsible for ordering supplies?
- c. What company will provide supplies?
- d. How many of each item should be available?
- e. If the person attends a day program, what supplies are needed at that site, and who is responsible?
- f. What supplies are needed when the person travels?

Specific Considerations for Respiratory Therapies

1. Use of Oxygen Therapy

- a. What is the specific physician order for the oxygen?
- b. Who will be permitted to administer the oxygen?
- c. What emergency preparedness principles should be followed for this person?
- d. How will EMS and utility companies be notified that the address has a person using oxygen?
- e. How often should the settings on the machine be checked?
- f. How often should the water bottles be checked?
- g. When should water bottles be refilled?
- h. What should be used to fill the water bottles?
- i. How often should the oxygen delivery system tubing and hoses be changed?
- j. What testing needs to be done to assure the oxygen concentrator is in proper working condition?

- k. Where will oxygen in use signs be posted?
- l. What should be done in the event of a power outage?
- m. What emergency supplies should be available?

2. Use of Breathing Treatments (Nebulizer)

- a. What is the specific physician order for the breathing treatments?
- b. Who will be permitted to administer breathing treatments?
- c. What emergency preparedness principles should be followed for this person?
- d. How will EMS and utility companies be notified that the address has a person using medical equipment for breathing?
- e. How often should the settings on the machine be checked?
- f. How often should the delivery system (tubing and mask or pipe) be changed?
- g. What testing needs to be done to assure the machine is in proper working condition?
- h. What should be done in the event of a power outage?
- i. What emergency supplies should be available?

3. Use of Bi-pap or C-pap

- a. What is the specific physician order for using Bi-pap or C-pap?
- b. Who will be permitted to administer this treatment?
- c. What emergency preparedness principles should be followed for this person?
- d. How will EMS and utility companies be notified that the address has a person using medical equipment for breathing?
- e. How often should the settings on the machine be checked?
- f. How often should the delivery system (hoses and mask) be changed?
- g. What kind of water should be used for the machine?
- h. What testing needs to be done to assure the machine is in proper working condition?
- i. What should be done in the event of a power outage?
- j. What emergency supplies should be available?

4. Use of the Pulse Oximeter

- a. Is a physician order required to check a pulse ox?
- b. Who can check a pulse ox?
- c. What testing needs to be done to assure the machine is in proper working condition?

5. Oxygen, Nebulizer, and Bi-pap/C-pap Delivery Systems

The tubing and hoses used to deliver oxygen and the medications in a nebulizer are known as the set up and they require care and management. The tubes and mask for a Bi-pap or C-pap machine can also be considered a set up. An oxygen concentrator is used to deliver oxygen and it requires care and maintenance.

- a. How often should the set-ups for oxygen, breathing treatments, and Bi-pap/C-pap be checked and what specific items are being looked for?
- b. What is the procedure to change the setup for
 - Oxygen?
 - Breathing (nebulizer) treatments?
 - Bi-pap or C-pap?
- c. What specific items should be used for the set up for
 - Oxygen?
 - Breathing (nebulizer) treatments?
 - Bi-pap or C-pap?
- d. Who will be responsible for changing this set up?
- e. When should the set-up be changed?
- f. What care and maintenance is required for
 - Oxygen concentrator?
 - Breathing (nebulizer) machine?
 - Bi-pap or C-pap machine?
- g. When should care of respiratory equipment be performed?
 - Oxygen concentrator?
 - Breathing (nebulizer) machine?
 - Bi-pap or C-pap machine?

6. Troubleshooting the Oxygen, Breathing Treatment, and Bi-pap/C-pap Delivery Systems

- a. What should be done if the humidification/oxygen delivery system is kinked?
- b. What should be done if the humidification/oxygen delivery system comes apart?
- c. What should be done if the humidification/oxygen delivery system can't be changed according to policy?

7. Troubleshooting the Oxygen Concentrator

- a. Who is permitted to troubleshoot the oxygen concentrator?
- b. What should be done if the oxygen concentrator cannot be returned to working condition?
- c. What should be done if there is a power outage?

Daily Care Considerations

1. What should be done if the person appears to have trouble breathing?
2. What should be done if the person has signs of other illness?
3. How should the person be positioned during breathing treatments?
4. How will the person use oxygen for travel, if ordered?
5. What equipment is necessary for overnight trips?
6. Where will the contact information for the supplier of the equipment be located?

Documentation

1. What should be documented and how often is documentation required for
 - a. Oxygen therapy?
 - b. Breathing (nebulizer) treatments?
 - c. Bi-pap or C-pap?
 - d. Pulse ox?
2. How and where should caregivers document
 - a. Oxygen flow rate?
 - b. Delivery of oxygen (via nasal cannula or face mask)?
 - c. Administration of breathing treatments?
 - d. Person's response to respiratory therapies?
 - e. Pulse ox readings and the amount of oxygen (liter flow) the person is on?
 - f. Information about the person's breathing?
 - g. Information about problems or concerns with any of these therapies?

Education

1. How will caregivers be educated about caring for the person using respiratory therapies at home?
2. How will new caregivers be trained?
3. How will the education provided be individualized for the person's specific treatment and care needs?
4. Who will provide the education? Will a "train the trainer" process be used?
5. How will caregivers demonstrate competency? How often?

6. How will caregivers be educated prior to the person's discharge from a hospital or nursing home?
7. How will non-residential caregivers (i.e., Day Program caregivers) be educated?
8. Who is responsible for educating the person's family members for home visits?
9. Where is the education documentation located?
10. What education will be provided to the person with the complex medical concern?

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Tracheostomy

A tracheostomy (trach) is a surgical opening through the front of the neck, into the trachea or windpipe. It is usually done when the airway is obstructed or the person can't breathe without assistance. Tracheostomies can be temporary or permanent. The opening in the neck is referred to as a stoma.

Often a tube is placed in this hole to facilitate breathing and management of secretions. The tube has two parts, an outer cannula and an inner cannula. The outer cannula stays in place at all times; the inner cannula is removed and cleaned or disposed of during care of the trach. There are different types and sizes of tubes that can be placed in the hole. Types of trach tubes include

- Cuffed
- Cuff less
- Fenestrated, Cuffed
- Fenestrated, Cuff less
- Metal

The patient's status and goals for treatment are considered by the doctor when deciding what type of trach tube to use. These different types have different care techniques, so it is important for caregivers to be aware of the type and also the size of tube used by the person in their care. Sometimes, as a person gets closer to the trach being removed permanently, the size and type of trach changes.

Seek Physician Guidance and Orders

Care and management of the tracheostomy is based on agency policies, best practice standards, and physician's orders. It is suggested that caregivers discuss the following with the physician:

- Type and size of tracheostomy tube
 - Cuffed
 - Cuff less
 - Fenestrated, Cuffed
 - Fenestrated, Cuff less
 - Metal
- Type, amount, and characteristics of secretions to be expected
- Recommendations for food and fluid intake
- Considerations for intake of food and fluids, such as positioning, consistency, or use of the trach prior to feeding
- Recommendation for supplies needed for person's care
- When to suction the person
- Frequency of suctioning
- Procedure for suctioning
- Use of oxygen and/or humidification

- Care of the trach stoma
- Recommendations for safe care of the individual with a tracheostomy
- Schedule for planned replacement of the tube
- When to notify the physician
- When to seek emergency care

Note: Some answers to these questions may be person specific and can be used to develop individualized written documents related to the person's care.

Points of Consideration for Caring for People with Tracheostomies

1. Scope of Care Guide

- Who and what does this care guide cover?
- Is this a generalized document?
- Is this a person specific document?
- How will information be communicated to other programs supporting the person?

2. Supplies Needed

- What supplies are needed?
- Who will be responsible for ordering supplies?
- What company will provide supplies?
- How many of each item should be available?
- If the person attends a day program, what supplies are needed at that site, and who is responsible?
- What supplies are needed when the person travels?
- Where will supplies be stored?

Specific Considerations for Tracheostomy

1. Use of the Tracheostomy

- Is a physician order required for routine and emergency care of the person with a trach?
- Who will be permitted to provide care for the tracheostomy?
- Do any specific care procedures for the tracheostomy require more than one person to be present?
- What is the exact technique and procedure to be followed for
 - Changing the dressing?
 - Changing the ties on the trach?
 - Cleaning or disposing of the inner cannula?

- Suctioning the person?
- Clearing the trach tube from secretions coughed up by the person?
- Administering CPR?
- e. When should trach care be performed?
- f. What equipment is needed to care for the person in an emergency situation?
- g. Where is the equipment for emergencies kept?
- h. What emergency preparedness principles should be followed for this person?
- i. How will EMS and utility companies be notified that the address has a person using life sustaining medical equipment?
- j. For the person using oxygen or humidification
 - How often should the settings on the machine be checked?
 - How often should the water bottles be checked?
 - When should water bottles be refilled?
 - What should be used to fill the water bottles?
 - How often should the oxygen delivery system tubing and hoses be changed?

2. Stoma Site Care

- a. Is a doctor's order required for specific care procedures per agency policy?
- b. What is the procedure for cleaning around the stoma?
- c. How often should the area be cleaned?
- d. What products should be used or avoided when performing stoma care?
- e. Who will be responsible for stoma care?
- f. What changes in the skin around the stoma should be reported to the physician?

3. Suctioning the Trach

- a. Is a physician order needed to suction the trach?
- b. Who can suction the trach?
- c. What is the exact procedure for suctioning the trach?
- d. Can the same catheter be used to suction the trach and the mouth?
- e. What should be done with used suction catheters?
- f. What should be done if the suction equipment does not work?
- g. What should be done in the event of a power outage?

4. Oxygen and Humidification Delivery Systems

Having a trach dries out the person's airway. Sometimes humidification is required and oxygen may be ordered as well. The tubing and hoses used to deliver the humidification and oxygen are known as the set up and they require care and management. An oxygen concentrator is used to deliver oxygen and it requires care and maintenance.

- a. How often should the humidification/oxygen set up be checked and what specific items are being looked for?
- b. What is the procedure to change the humidification/oxygen delivery setup?
- c. What specific items should be used for the set up?
- d. Who will be responsible for changing this set up?
- e. When should the set-up be changed?
- f. What care and maintenance does the oxygen concentrator require?
- g. When should care of the oxygen concentrator be performed?

5. Troubleshooting the Humidification/Oxygen Delivery System

- a. What should be done if the humidification/oxygen delivery system is kinked?
- b. What should be done if the humidification/oxygen delivery system comes apart?
- c. What should be done if the humidification/oxygen delivery system can't be changed according to policy?

6. Troubleshooting the Oxygen Concentrator

- a. Who is permitted to troubleshoot the oxygen concentrator?
- b. What should be done if the oxygen concentrator cannot be returned to working condition?
- c. What should be done if there is a power outage?

7. Troubleshooting the Trach

- a. How often should the security of the trach be checked?
- b. What should be done if the trach ties are loose?
- c. What should be done if the trach comes out?
- d. What should be done if the inner cannula cannot be cared for according to schedule?
- e. What should be done if the non-disposable inner cannula is lost or missing?

Daily Care Considerations

- 1. What should be done if the person appears to have trouble breathing?
- 2. What should be done if the person has signs of other illness?
- 3. What should be done if secretions are thicker than normal?
- 4. What should be done if there is a larger amount of secretions than normal?
- 5. How should the person be positioned during trach care?
- 6. What does mouth care mean for the person with a trach and how often should it be done?

7. Should the person take a bath or shower?
8. What type of clothing should be worn to accommodate the trach?
9. Does the trach require any kind of cover to prevent foreign objects from entering?
10. Where will the contact information for the supplier of the equipment be located?
11. For the person requiring emergency care for the trach
 - What information should be taken to the hospital?
 - What equipment should be taken to the hospital?

Documentation

1. What should be documented and how often is documentation required?
2. How and where should caregivers document?
3. What is the condition of stoma?
4. Care of the trach?
5. What was the person's response to trach care?
6. Was there use of oxygen and/or humidification?
7. How is the person breathing?
8. Were there any difficulties?

Education

1. How will caregivers be educated about caring for the person with a trach, including all care aspects, signs of distress, and emergency management?
2. How will new caregivers be trained?
3. How will the education provided be individualized for the person's type of trach and care needs?
4. Who will provide the education? Will a "train the trainer" process be used?
5. How will caregivers demonstrate competency? How often?
6. How will caregivers be educated prior to the person's discharge from a hospital or nursing home?
7. How will non-residential caregivers (i.e., Day Program caregivers) be educated?
8. Who is responsible for educating the person's family members for home visits?
9. Where is the education documentation located?
10. What education will be provided to the person with the complex medical concern?

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Template for Care Guide Development

Scope of (Topic Title)

Supplies Needed

Specific Considerations

Daily Care Considerations

Documentation

Education

Created: _____

Reviewed: _____

Approved: _____

Sample Template for Care of a Person with a Laceration (Cut)

Scope of Guideline

This is a general guideline pertaining to care of the person with a cut. Any caregiver certified in First Aid in both residential and Day Program settings can care for the person with a cut.

Supplies Needed

- Washcloth
- Soap
- Water
- Adhesive bandage
- Gloves

Specific Considerations

1. Wash the area with soap and water. Pat dry.
2. If still bleeding, apply pressure.
3. If unable to stop the bleeding from the cut, activate EMS.
4. Notify a physician if the cut appears deep, if sensation or movement is impaired, and if emergency medical treatment is required.

Daily Care Considerations

1. Change the bandage once daily until the cut is healed.
2. Notify the physician if signs of infection (redness, swelling, warmth, drainage, foul odor) are noted.

Documentation

1. Document the size of the cut, and describe what it looks like with each dressing change in the Daily Notes section of the person's chart.

Education

- All caregivers are trained in this care procedure in First Aid training.
- First Aid training is completed on an annual basis.

Created: _____

Reviewed: _____

Approved: _____

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