



My Care Passport & Local Medical Care Card

**Advocacy Tools Aimed At Improving Communication
& Healthcare Quality For Individuals With IDD**

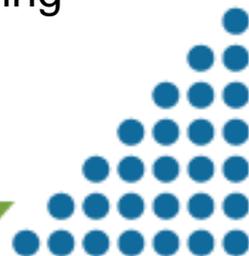
Developed and Presented by Office of Community Quality Improvement in collaboration with the Office of Integrated Health Supports Network at the Virginia Department of Behavioral Health and Developmental Services





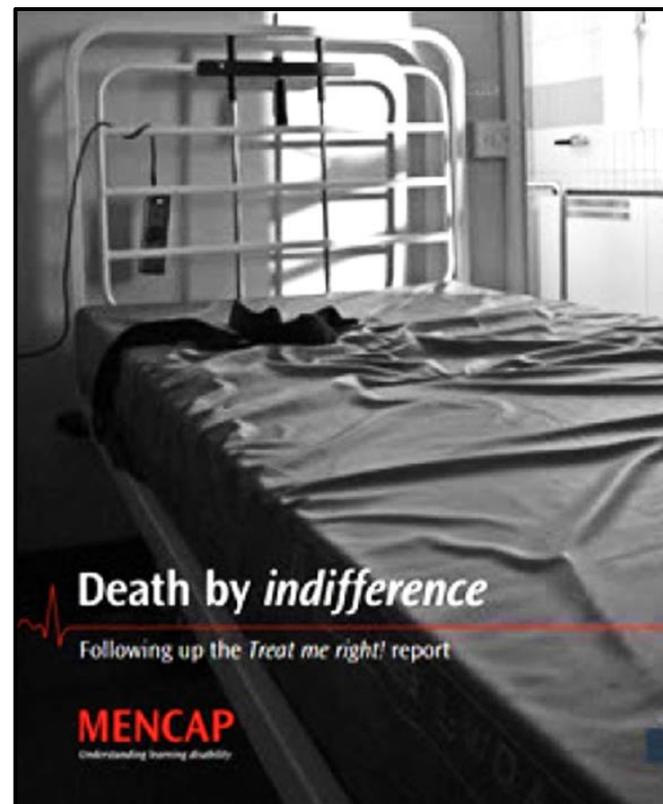
Learning Objectives

- Identify the symptoms of UTI and Urosepsis.
- Describe how to use the Decision Tree to determine if the symptoms the individual is experiencing are a medical emergency or not.
- Describe why the My Care Passport was developed and its purpose.
- State how the My Care Passport can be used as a communication and advocacy tool in acute care settings.
- Describe how the My Care Passport can improve healthcare quality.
- Summarize the information contained in the Consent, Medicaid Waiver, and Discharge Requirements Tip Sheets and their purpose.
- Describe how the use of the Local Medical Care Card can assist with helping individuals receive the healthcare they need in a timely manner.



Why was a communication and advocacy tool needed?

- Individuals with IDD did not always receive the right healthcare.
- Many deaths were determined to be from preventable causes.
- A disproportionate number of individuals with IDD were dying in acute care hospitals when compared to the general public.



A lack of communication was identified as a barrier to quality care.



The breakdown in communication occurred because...

Community Caregivers:

- Did not always know what information hospital staff needed to know.
- Incorrectly assumed that all acute care staff had experience and training focused on caring for individuals with IDD.

Acute Care Hospital Staff:

- Did not always know the right questions to ask.
- Lacked experience and training focused on caring for individuals with IDD.
- Did not know how to “connect” with individuals on a person-to-person basis.



Poor Communication + Poor Information Sharing

=

Poor Quality of Care



My Care Passport was Created

- The My Care Passport is an Americanized version of the Hospital Passport.
- Its use is voluntary.
- Improves communication and information sharing between acute care staff and community caregivers.
- Promotes person-centeredness by familiarizing hospital staff with the unique needs, abilities, interests, likes and dislikes of individuals with IDD.

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My Care Passport

If I go to the hospital this document needs to go with me. It is essential reading for all staff who provide care or services to me. It gives important information about me. This document should be kept with me at my bed, in my notes, and used when you talk with me.

My Care Passport

My Name is: _____

I like to be called: _____

The type of home I live in is: _____
 Example: Group home, Family home, Supported living

The level of support I need and the hours of support I get a day are: _____

Who can give consent to treat me and their contact information: _____

The people who are important to me and who can give you information about me: _____

My drug and food allergies and/or adverse drug reactions:

Agency Name: _____

Address: _____

Phone Number: _____

Signature: _____ Date: _____

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The 1st Page

- The first page holds basic information regarding the individual.
 - Their photo.
 - Their name.
 - Nick name.
 - Consent information.
 - Important people.
 - Allergies and adverse reactions.
 - Provider agency information.
 - Signature of person completing the “My Care Passport”.

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Address:

Phone Number:

Signature: _____

Date: _____

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Page 1 of 4

The 2nd Page

- The second page holds the “**Things you need to know about me**”.
- This section is in **RED** indicating highest importance.
 - Communication.
 - Pain.
 - Eating & drinking.
 - How medications are taken.
 - Support during medical treatments.
 - Vision & hearing.
 - Safety.
 - Behaviors.

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 My Care Passport

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Things you need to know about me:

Communication — How well I use and understand speech.
 How I communicate YES or NO. The ways I communicate and show how I feel.

Pain — How do I show when I'm in pain and how to support me?

Eating & Drinking — What help I need and what food allergies or intolerances I have.
 Does my food need to be cut up or the texture changed? Is there a risk for choking? Do I use special equipment to eat or drink?
 Do I need help filling in menus? (Also, see likes and dislikes section).

How do I take my medications & how to support me with medical treatments —
 One tablet at a time, crushed mixed in applesauce, and all liquids?
 Do you need to check and make sure I swallowed? Taking my vital signs, doing a blood test, or giving an injection.

My vision and hearing — Do I have any problems with seeing or hearing? Do I use an aid to hear or see?

How to keep me safe — Do I wander? Could I fall out of bed or climb out? **STAY SAFE**

How to support me when I'm anxious, worried or upset. Behaviors I have that might be challenging or cause risk —
 What you can do to support me with my behaviors, things which help me relax.

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The 3rd Page

- The third page holds “**Things you should know about me**” are in **YELLOW**.
 - Toileting.
 - Personal care needs.
 - Mobility needs.
 - Sleeping.
- Then in **GREEN** are the “**Things that are important to me**”.
 - Likes.
 - Dislikes.
 - Typical behavior.

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My Care Passport



Things you should know about me:

How I use the toilet & my personal care needs — Example: I am incontinent of bowel and/or bladder. I can't walk on my own to the bathroom or clean myself after I use the toilet? What support do I need for personal care? 

★ Moving around — Do I need help to move around? Do I use a walker, wheelchair, or need help repositioning? 

Sleeping — What are my sleep patterns or routines at bed time? Do I get up during the night? How often should you check on me at night? 

Things that are important to me:

Things I like — Things important to me, I enjoy and help me to relax. Foods and drinks I like. Clothes and shoes I like to wear, how I like my hair done, my favorite music, T.V. programs, and activities. 

Things I don't like — Things that make me unhappy, anxious or scared. Foods and drinks I don't like. Ways I don't like to be treated. 

How I usually am — Examples: I sleep a lot, I am usually very quiet, I am very active during the day.

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Page 3 of 4

The 4th Page

- The fourth page is for additional information.
 - Passport Updates in **BLUE**.
 - Additional notes in **PURPLE**.

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My Care Passport

Passport Updates — This section is to be completed by hospital staff when the individual's condition has changed affecting the information on this Care Passport and/or the individual is transitioning to a different level of care.

Additional Notes — Any additional information which might be needed to provide safe quality care to this individual.

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Page 4 of 4



The Consent Tip Sheet

The Consent Tip Sheet

- Shares information about medical care and treatment consent for individuals.
- Indicates who can make medical decisions and who can receive personal health information (PHI) relating to the individual based on their role.



Consent Tip Sheet

	Definition – The Chart below is to help with surrogate decision - making for persons who lack capacity. <i>Note: Patients are assumed to have capacity unless determined otherwise by an up-to-date capacity assessment.</i>	Person who can make medical decisions	Person authorized to receive PHI
Medical Power of Attorney (MPOA)	Selected by the patient in an advanced directive as the person authorized to make decisions for them if they are ever incapacitated.	Yes	Yes
Legal Guardian	A court appointed guardian has authority to make medical decisions.	Yes	Yes
Legal Surrogate Decision Maker (Next of Kin)	When there is no MPOA, no guardian, and the patient lacks capacity to make medical decisions. This is a family member or close acquaintance who is next in line following Virginia law on surrogate decision-making and who is willing to serve in the role of surrogate decision-maker.	Yes	Yes
Authorized Representative (AR)	A person authorized to receive and disclose medical information. To consent for treatment and services within a designated provider/setting – such as a group home, day program, or work program.	No Not for hospital care decisions. Yes For decisions in the location identified by the AR authorization.	Yes
Designated Direct Support Professionals (DSP)	A person designated by a patient to provide any needed assistance while the patient is in the hospital and in the community, including assistance for communication, and basic care needs.	No	Yes
Community Agency Care Providers	A community agency care provider who supports the individual to live independently in their own home under a Medicaid Waiver.	No	Yes

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Page 1 of 1



The Discharge Requirements Tip Sheet

The Discharge Requirements Tip Sheet

- Communicates best practice discharge instructions for individuals in Virginia’s Waiver System.
- Is focused on individuals who reside in a DBHDS licensed setting.
- Aimed at individuals primarily supported by laypersons.



Discharge Requirements Tip Sheet

Note: All individuals beginning discharged into the community require a written order for each medication, treatment, assessment, measurement, protocol, or equipment.

Information needed for unlicensed laypersons to administer medications under a Medicaid Waiver system.

Prescription Requirements	<ul style="list-style-type: none"> • A complete written prescription for each medication, and or oxygen therapy, signed by the physician. Must also include: <ul style="list-style-type: none"> – Purpose of medication and expected therapeutic response. – Medication or food interactions, if any. – Stop date for medication, if applicable. – Specialty administration and/or storage instructions if any. – Parameters for ‘holding’ the dose. (Example: do not give if pulse is lower than...). • All over-the-counter (OTC) medications have the same requirements as prescriptions drugs.
PRN Medication Requirements	<ul style="list-style-type: none"> • Specific instructions must be written to include all of the above and: <ul style="list-style-type: none"> – Exact dosage to be given. – Clear parameters for administering. (Example: give if crying for more than 5 min.) – Expected therapeutic response. (Example: individual should have a BM within 1 hour.) – Follow-up instructions, if therapeutic response is not achieved.
Psychotropic Medication Requirements	<ul style="list-style-type: none"> • All psychotropic medications require a stated diagnosis and a rationale. • May require prescriber to complete an additional form to indicate reason medication is being prescribed.
Care Requirements & Therapies	<ul style="list-style-type: none"> • Follow-up requirements to the Primary Care Physician or required Specialist. • Written orders for all medications, treatments, and therapies for each specialist. • Written orders for Home Health nursing. • Written protocols for all care concerns, such as: measuring vital signs, positioning, aspiration prevention, respiratory therapy, dietary modifications, wound care, etc.
Durable Medical Equipment Requirements	<ul style="list-style-type: none"> • All prescriptions should include a diagnosis and reason for equipment. • Physician may write a list of possible adaptive equipment needs, to be assessed by the Physical Therapist.

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Page 1 of 1

The Medicaid Waiver Tip Sheet

The Medicaid Waiver Tip Sheet

- Communicates a simplified explanation of Virginia's Medicaid Waiver Support System for individuals with IDD.
- Shares several resources for more in-depth information about Virginia's Medicaid Waiver Support System, if desired.



Medicaid Waiver Services Tip Sheet

What is a Waiver?	<ul style="list-style-type: none"> • In addition to Medicaid, a Medicaid Waiver is a long-term support system for someone who has long-term care needs and or could live in an institution, like an individual with an intellectual and/or developmental disability. • Once a Waiver is assigned, there are several services available. Frequently used services include: <ul style="list-style-type: none"> – Assistants who work 1 to 1 with the person, – Respite care so parents can have a break, – Group home supports by direct support professionals (DSPs) where a person with a developmental disability lives in a home shared by other people with disabilities, – Long term employment, – Meaningful day services, – Assistive technology, – Environmental modifications, – Nursing, and more. • These services are offered at no or very low cost.
Waiver Options	<ul style="list-style-type: none"> • Community Living Waiver (CL) – is for youth and adults who have extremely high medical, behavioral, or support needs. It provides 24/7 active services, delivered by direct support professionals (DSPs). • Family and Individual Supports Waiver (FIS) – is for children and adults who need supports from between a few hours to most hours of the day, including overnight monitoring in some cases. • Building Independence Waiver (BI) – is for those 18 years and older who can live and work with a fair amount of independence, but need drop in supports. • Commonwealth Community Care Waiver (CCC+) – is for people who have a developmental disability or are over the age of 65 and have significant medical needs; primarily attendant and respite care, and some nursing.

Resources

- Individuals with intellectual and developmental disabilities (IDD) who utilize the Medicaid Waiver services are assessed every three years with a test called the Supports Intensity Scale (SIS) to measure the intensity of their needs. <https://dbhds.virginia.gov/developmental-services/waiver-services>
- Individuals with IDD who have more needs receive a higher reimbursement rate for some of their services. <https://dbhds.virginia.gov/library/developmental%20services/mlmc%20services%20and%20support%20options%20for%20adults%206-30-16.pdf>
- Waiver information. <https://dbhds.virginia.gov/developmental-services/my-life-my-community-waiver>
- My Life, My Community. <https://www.mylifemycommunityvirginia.org/>
- Waiver Options. <https://dbhds.virginia.gov/library/developmental%20services/mlmc%20services%20and%20support%20options%202016%20final%206%2030%2016.pdf>

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Local Medical Care Card

- The Local Medical Care (LMC) card shares the individual's name, home address, and phone number, as well as the address & contact information for:
 - Primary Care Provider (PCP).
 - Local Urgent Care Center and alternative.
 - Hospital Emergency Room and alternative.
- The distance of all the above from the individual's home.



Complete the OIHSN "My Care Passport"
<https://dbhds.virginia.gov/wp-content/uploads/2022/09/DBHDS-My-Care-Passport-9.25.22.pdf>
 for every individual who is taken to visit a healthcare professional such as to the primary care provider, hospital emergency room, or urgent care.

Individual's Name: _____

LOCAL MEDICAL CARE CARD	Preferred/Nearest
Group Home Information: Name: ABC Group Home Location: 100 Sunnyvale Drive Contact Number: (804) 456-7890 Information for 911: House is white with red shutters and at the end of the street on the right. Please come in the left side door of the house.	
Primary Care Provider: _____ Distance: _____ Name: _____ Location: _____ Contact Number: _____	
Does Primary Care Provider offer Urgent Care onsite? Yes No Name: _____ Location: _____ Contact Number: _____	
Local Urgent Care Center: _____ Distance: _____ Name: _____ Location: _____ Contact Number: _____	
Alternative Urgent Care Center: _____ Distance: _____ Name: _____ Location: _____ Contact Number: _____	
Hospital Emergency Room: _____ Distance: _____ Name: _____ Location: _____ Contact Number: _____	
Alternative Hospital Emergency Room: _____ Distance: _____ Name: _____ Location: _____ Contact Number: _____	
Freestanding Emergency Room: _____ Distance: _____ Name: _____ Location: _____ Contact Number: _____	

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Page 1 of 1



UTI Case Study #1





Bobbie is a non-verbal 35-year-old male with severe & profound DD. He is completely dependent on caregivers for all activities of daily living (ADL's) and wears adult briefs due to bowel & bladder incontinence. He uses a condom catheter for increased independence at the day program. He is dependent on caregivers to change his adult briefs and empty his catheter bag at both sites. **BASELINE**

For the last 3-4 days, Bobbie's urine has been dark yellow, cloudy and foul smelling. He has had increased behaviors and started kicking and fighting with his caregivers when being repositioned. He has become increasingly angry and aggressive with caregivers during any interaction. He began refusing to eat, or drink yesterday and also started crying out and fighting when being bathed or dressed. **CHANGES**

Early this morning Bobby started sweating, shivering, crying loudly, and breathing very fast, as if he couldn't catch his breath. His heart rate was 110 (high). His blood pressure was 80/48 (low). He is lethargic (lifeless), and his skin is pale and clammy. **CHANGES**

The Individual's Health Baseline

Worsening Chronic Condition
or New Illness

**CHANGE
OCCURS**

Worsening Chronic
Condition or New Illness





What Should Be Done Next?

1. **What should Bobbie's caregivers do next?**
 - a. Call his primary care provider (PCP) and make the next possible appointment.
 - b. Take him to the urgent care when you have time this evening.
 - c. Call 911 immediately.
 - d. Do nothing and put him to bed with extra blankets because he shivering.

**First: Compare UTI Symptoms
verses
Sepsis/Urosepsis Symptoms**



UTI is not a medical emergency, but when symptoms of UTI are recognized, individuals with IDD **should be assessed, diagnosed and treated as soon as possible.**

Symptoms of UTI

- Dysuria (painful or difficult urination. **Maybe**)
- Fever. **Maybe**
- Frequent and urgent urination.
- Nocturia (excessive urination at night).
- Hematuria (blood in urine). **Maybe**
- Malaise (feeling ill or weak). **Yes**
- Lower abdominal pressure, pain or cramping. **Maybe**
- Urinary incontinence. Baseline.
- Loss of appetite. **Yes**
- Mental confusion.
- Irritability or agitation. **Yes**
- Chills, nausea or vomiting. **Yes**
- Dark yellow, cloudy or foul-smelling urine. **Yes**

Sepsis & Urosepsis (a UTI that has progressed to sepsis) is **ALWAYS A MEDICAL EMERGENCY.** When symptoms are recognized, call 911.

Symptoms of Urosepsis

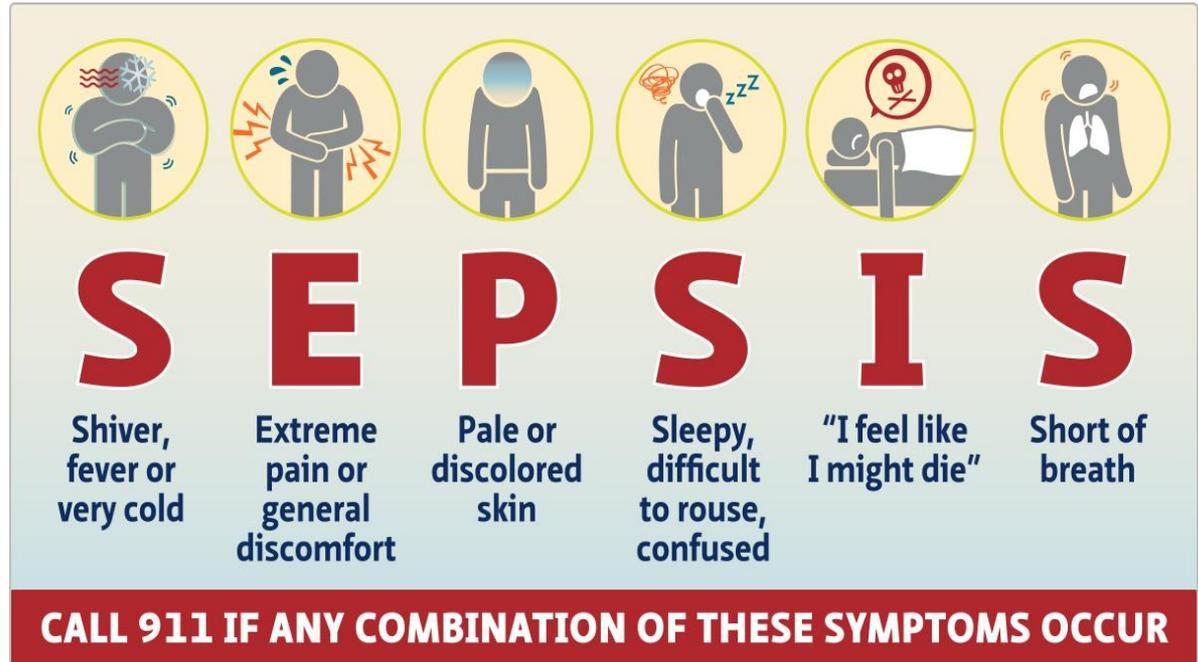
- Low blood pressure
- Rapid heart rate (pulse)
- High/fast respiratory rate (Tachypnea)
- Difficulty breathing
- Shaking chills
- Extreme pain
- Sepsis rash.
- Clammy or sweaty skin.



Bobbie Has UTI with Sepsis/Urosepsis Symptoms.

SEPSIS

- Life-threatening.
- Must act quickly.
- Administration of IV antibiotics should begin within one hour, once symptoms are identified.
- Each one-hour delay in IV antibiotic treatment drops the survival rate by 8%.



The infographic displays the word 'SEPSIS' in large red letters, with each letter corresponding to a symptom. Above each letter is a circular icon: 'S' shows a person shivering with a snowflake; 'E' shows a person in pain with lightning bolts; 'P' shows a person with pale skin; 'S' shows a person sleeping with 'ZZZ' and a brain icon; 'I' shows a person in bed with a skull and crossbones; 'S' shows a person with a stethoscope. Below the letters are descriptions of each symptom. At the bottom, a red banner reads 'CALL 911 IF ANY COMBINATION OF THESE SYMPTOMS OCCUR'.

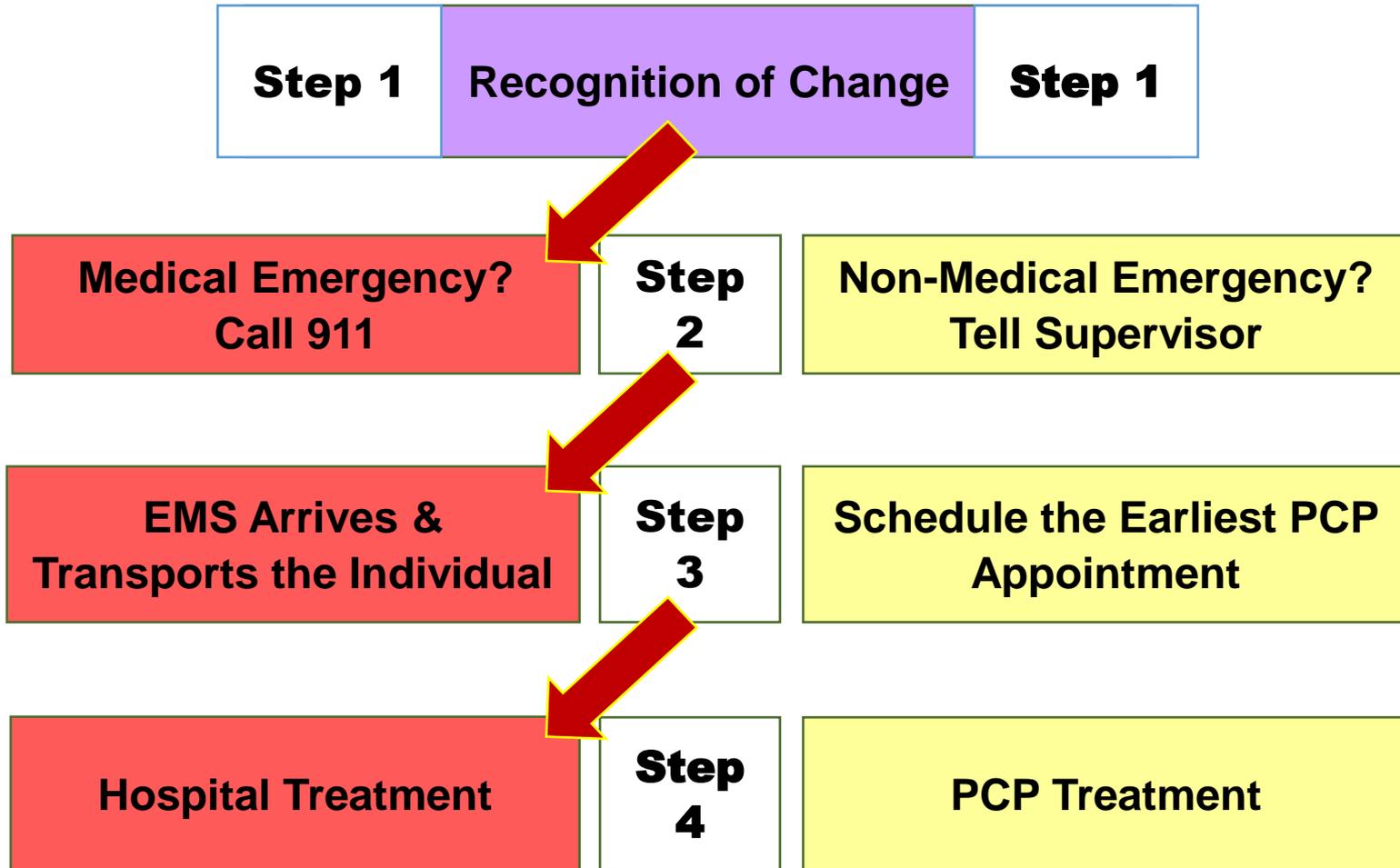
					
S	E	P	S	I	S
Shiver, fever or very cold	Extreme pain or general discomfort	Pale or discolored skin	Sleepy, difficult to rouse, confused	"I feel like I might die"	Short of breath

CALL 911 IF ANY COMBINATION OF THESE SYMPTOMS OCCUR

Call 911 For Sepsis/Urosepsis Symptoms



The Decision Tree





Additional Advocacy in the ER

- Go to the ER to advocate for the individual whenever possible, even when the individual is transported by ambulance.
- Communicate the individual's baseline functioning (their typical functioning).
- Communicate any recent changes observed, when they started, what the progression has been, and what you know, as best as you can.
- Try to be as specific as possible:
 - “Bobbie has severe and profound IDD.”
 - “He is completely dependent on caregivers for his ADL's.”
 - “He is incontinent of bladder and bowel.”
 - “He wears adult briefs and a condom catheter,”
 - “Bobbie's urine has been yellow, cloudy and foul smelling for 3-4 days.”
 - “Bobbie has had increased behaviors over the last week, which may be due to pain.”
 - “He was crying loudly, shivering and panting like he couldn't catch his breath this morning before we called 9-1-1.”





Emergency Room Advocacy Card

Condition	Diagnostic Test or Clinical Assessment (CA)
UTI	Urinalysis, CBC, CA
Sepsis	CBC, CA, Vital Signs, Lactic Acid Levels
Dehydration	CBC, CA, Vital Signs
Constipation	Abdominal X-ray, CA
Pressure Injury	CA
Falls	X-ray, CT, MRI, CA
Aspiration	Chest X-ray, Vital Signs
Seizures	EEG

Definitions	
CBC	Complete Blood Count
CA	Clinical Assessment
CT	Computed Tomography Scan
MRI	Magnetic Resonance Imaging
EEG	Electroencephalogram

Who to seek help from at the hospital –
 The patient advocate, the charge nurse, the medical director
 or the hospital social worker.



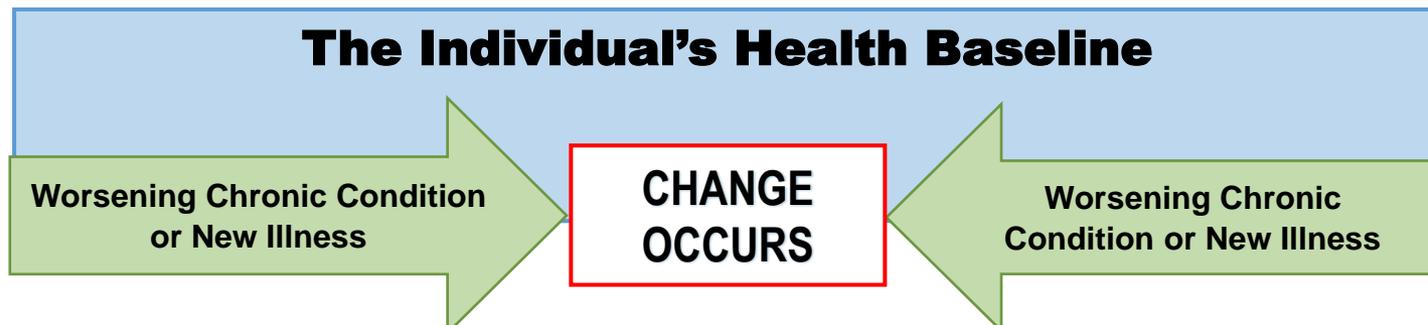


UTI Case Study #2



Patty is a 65-year-old female with moderate DD. She is incontinent of bowel, and bladder at night and wears an adult briefs to bed. During the day, without warning, she takes her pants off, then runs to the bathroom to use the toilet. She has a toileting schedule to encourage her to use the bathroom instead of a brief. She can minimally assist with activities of daily living such as dressing, bathing, and eating. She is able to verbally communicate in simple words but doesn't speak in complete sentences. **BASELINE**

Three days ago, she finished a 7-day course of oral antibiotics for a UTI. Staff noticed she has been picking at her perineal area for the past two days more than normal and has been in and out of the bathroom all day. When she does urinate, her urine is medium yellow in color. Patty's brief has been dry in the morning when it is usually soaked with urinate and she has been refusing to drink water since she started taking the antibiotic. **CHANGES**





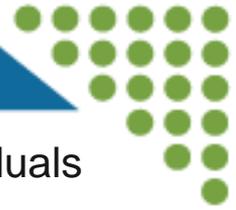
What Should Be Done Next?

Patty's caregivers called her primary care provider's (PCP) office to schedule an appointment, but he is out of town for four days and there is no one covering for him.

1. **What should Patty's caregivers do next?**
 - a. Call her PCP and take the next possible appointment even if it is 5 days away.
 - b. Take Patty to the urgent care listed on her Local Medical Care card today.
 - c. Call 911 immediately.
 - d. Do nothing but keep a close eye on her.

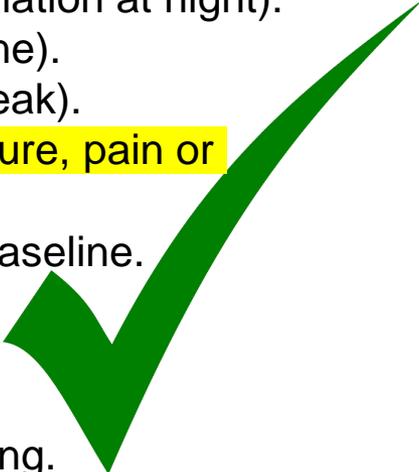
First: Compare UTI Symptoms verses Sepsis/Urosepsis Symptoms





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 - Fever.
 - Frequent and urgent urination. **YES**
 - Nocturia (excessive urination at night).
 - Hematuria (blood in urine).
 - Malaise (feeling ill or weak).
 - Lower abdominal pressure, pain or cramping. **Maybe**
 - Urinary incontinence. Baseline.
 - Loss of appetite. **Yes**
 - Mental confusion.
 - Irritability or agitation.
 - Chills, nausea or vomiting.
 - Dark yellow, cloudy or foul-smelling urine. **Yes**
- 

Symptoms of Urosepsis

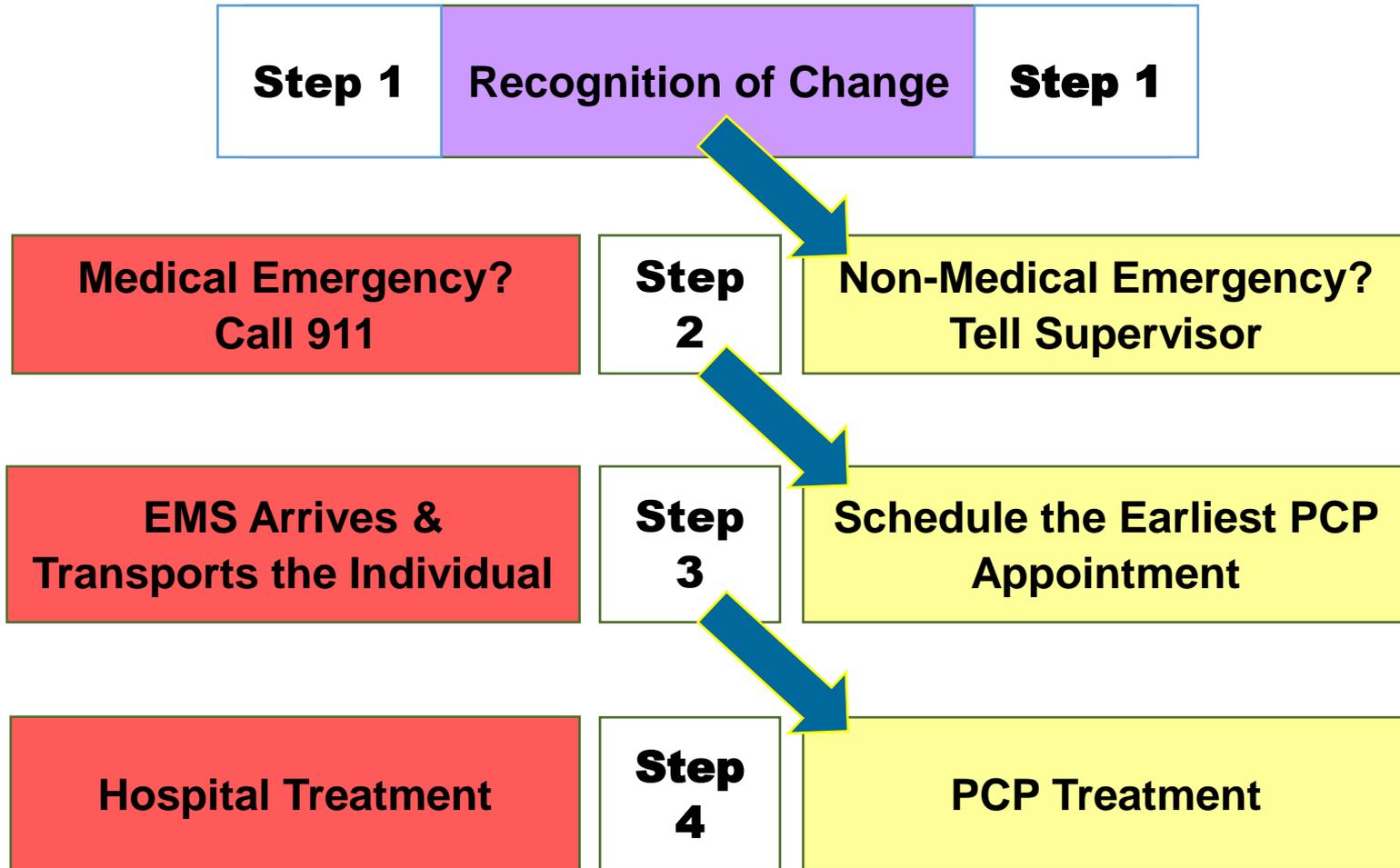
- Low blood pressure
- Rapid heart rate (pulse)
- High/fast respiratory rate (Tachypnea)
- Difficulty breathing
- Shaking chills
- Extreme pain
- Sepsis rash.
- Clammy or sweaty skin.

Patty has UTI symptoms, but she does not have any life-threatening symptoms, so it is not a medical emergency.





The Decision Tree



Local Medical Care Card

- Take Patty to the Urgent Care Center listed on her Local Medical Care Card.
- Take a copy of the Medication Administration Record (MAR), and the her My Care Passport with you.



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<https://dbhds.virginia.gov/wp-content/uploads/2022/09/DBHDS-My-Care-Passport-9.25.22.pdf>
 for every individual who is taken to visit a healthcare professional such as to the primary care provider, hospital emergency room, or urgent care.
 Individual's Name: _____

LOCAL MEDICAL CARE CARD	Preferred/Nearest
Group Home Information: Name: ABC Group Home Location: 100 Sunnyvale Drive Contact Number: (804) 456-7890 Information for 911: House is white with red shutters and at the end of the street on the right. Please come in the left side door of the house.	
Primary Care Provider: Name: _____ Location: _____ Contact Number: _____	Distance: _____
Does Primary Care Provider offer Urgent Care onsite? Yes No Name: _____ Location: _____ Contact Number: _____	
Local Urgent Care Center: Name: _____ Location: _____ Contact Number: _____	Distance: _____
Alternative Urgent Care Center: Name: _____ Location: _____ Contact Number: _____	Distance: _____
Hospital Emergency Room: Name: _____ Location: _____ Contact Number: _____	Distance: _____
Alternative Hospital Emergency Room: Name: _____ Location: _____ Contact Number: _____	Distance: _____
Freestanding Emergency Room: Name: _____ Location: _____ Contact Number: _____	Distance: _____

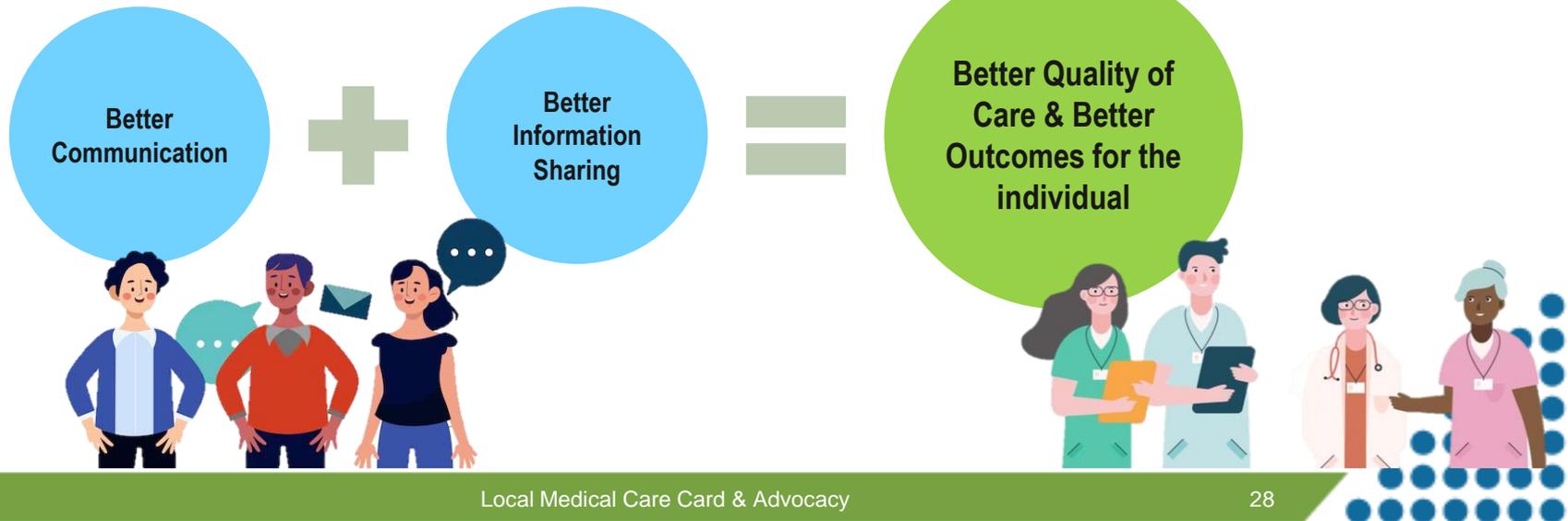
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Page 1 of 1



Conclusion

- The **My Care Passport** and **Tip Sheets** are advocacy tools that can improve communication and information sharing between community caregivers and acute care staff.
- The **Local Medical Care Card** will take the guess work out of getting the individual with IDD to the healthcare they need.
- The **ER Advocacy Card** will ...
 - Helps caregivers know which diagnostic tests to advocate for to ensure positive outcomes in a timely manner for the individual with IDD.
 - Whom to seek help from if the individual's human rights are being violated or their needs are being ignored or neglected.





Questions

- Please direct any questions or concerns regarding this training to:
 - Tammie Williams, RNCC, Community Nursing and Educational Lead.
tammie.Williams@dbhds.virginia.gov
 - Marylou Bryan, RNCC, Educational Development.
marylou.bryan@dbhds.virginia.gov
 - Joy Richardson, RNCC, Region 4.
joy.Richardson@dbhds.virginia.gov
 - Brian Phelps, BCBA.
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Thank You!





References

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