Tip Sheet # 6

How to Manage Specific Problems the Stroke Survivor May Have

It is not unusual for a person who has had a stroke to have some problems after they go home. Not all stroke survivors are the same. Some have certain problems. Others do not. Below is a list of problems or complications that the survivor **may or may not** have after stroke:

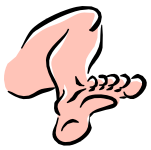
- **Seizures** or partial seizures that might cause convulsions
- **Blood clots** in the legs or elsewhere in the body
- **Pneumonia** from fluid in the lungs or infection
- **Bedsores** from sitting or lying in one place too long
- **Limb contractures** where the joints in the arms or legs become harder to move, or they become stiff. There is less range of motion of the joints in the arms or legs.
- **Shoulder pain** from lack of support or exercise of the arm
- **Other types of pain**
- **Urinary tract infection** (kidney or bladder infections)
- **Loss of bladder control** (urinary incontinence) – can't get to the bathroom in time, or they don't know when they have to go.
- **Loss of bowel control**
- **Constipation**
- **Dizziness, lightheadedness, or balance problems**
- **Feeling tired or can't get enough sleep**
- **Depression –** don't feel like they are going anywhere or doing anything worthwhile.

Seizures or partial seizures that might cause convulsions

- **A seizure** occurs when the brain does not work properly after a stroke. Some stroke survivors have seizures or partial seizures.
- Seizures can happen because of swelling in the brain. They can also be caused by problems with electrical activity in the brain.
- Convulsions will usually happen with a seizure. Arms and legs may move around or shake rapidly. There may be drooling or frothing at the mouth. The person may not know what is happening to them.
- **Call 911 if the survivor has a seizure.**
- Try to keep the person from hitting their head. Move objects out of the way so they don't hit them with their arms or legs.
- **Do not try to put anything in a person's mouth while they are having a seizure.**

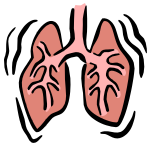
- **Partial seizures** affect only a certain part of the brain.
    - Simple partial seizures do not affect awareness or memory.
    - Complex partial seizures can affect awareness, memory, or may cause certain behaviors.
    - There are many possible symptoms with partial seizures. Some of these might include:
        - Unusual movement of the head, arms, or legs
        - Muscle spasms with twitching or jerking of arms or legs
        - Picking at one's clothing
        - Staring or eyes moving side to side
        - Numbness or tingling (like ants on the skin)
        - Hallucinations or seeing, smelling, or hearing things that are not there
        - Blackout spells or memory loss
        - Sudden changes in mood, such as anger, fear, panic, joy, or laughter
        - Trouble speaking, drooling, grunting, or snorting
        - Other symptoms not on this list

- **Call 911 if the survivor has a partial seizure.**



Blood clots in the legs or elsewhere in the body

- Blood clots can form in the legs or other parts of the body. These blood clots can break off and travel to other areas of the body.
    - A blood clot that travels to the brain can cause a stroke.
    - A blood clot that travels to the heart can cause a heart attack.
    - A blood clot that travels to the lungs can cause breathing problems.
- Ask the survivor to move their legs and ankles. Try to get them to do prescribed exercises. Ask the doctor if they think they might need blood thinners.



Pneumonia

- After a stroke, fluid can gather in the lungs. This fluid can cause breathing problems. It can also cause an infection in the lungs.
- Ask the survivor to take deep breaths every now and then. Try to get them to do prescribed exercises.
- Call the doctor if they have swallowing problems. Fluids that go down wrong can get into the lungs. This can cause pneumonia.

Bedsores

- Bedsores are sores on the skin. Pressure on parts of the body causes sores to form. These sores can be hard to heal.
- Look at the survivor's skin. Look for any red areas. They are usually over bones. Hips, buttocks, elbows, and heals are where sores usually form.
- Call the doctor or nurse if you notice any sores. Keep the survivor from lying on that area.
- Ask the survivor to not sit or lay in one place for more than 2 hours. When in bed, have them turn over every 2 hours when they are awake. When in a chair, ask them to lean from side to side. A special cushion may be needed.

Limb contractures

- Limb contractures are where the arm or leg becomes stiff and cannot move. There is less range of motion of the arm or leg.
- Help the survivor do range of motion exercises. Start at the toes. Have them wiggle or move their toes, then their ankles, knees, hips, back, shoulders, elbows, wrists, hands, fingers, and neck. Try to have them move each joint every direction possible.
- If they are paralyzed or cannot move certain areas of the body, have them use their other hand to move the paralyzed joints. **Do not force the joints to move too far.** Stop if there is pain.
- Range of motion exercises should be done every day to prevent limb contractures.
- Ask the doctor, nurse, or physical therapist how to do range of motion exercises if you have questions.

Shoulder pain or other types of pain

- Shoulder pain can be from lack of support or exercise of the arm.
- Pain in other areas can be from:
    - Lack of exercise or stiffness of joints. Limb contractures can be painful. Bedsores can also be painful.
    - **Pain can be a sign that something is wrong.** Chest pain can be a sign of a heart attack. A sudden severe headache could be another stroke. **Call 911 if there is chest pain or a sudden severe headache.**

- How can I as the caregiver help with pain?
    - Support the paralyzed arm so that it does not hang free all the time. Ask an occupational therapist for suggestions on how to support the arm. Move the body part that hurts to a more comfortable position.
    - Exercise the paralyzed arm. Do range of motion exercises using the other hand to help. Use gentle exercise to stretch the body part that hurts. Support the body part that hurts on a pillow.
    - **Do not pull on the paralyzed arm to help the survivor move, get up, or walk.** Injury can result.

- Pay attention to where the pain is. **Call 911 for chest pain or a sudden severe headache.** Call the doctor if the survivor has pain somewhere new. Something could be wrong.
- Try to take your survivor's mind off of the pain.
  - Use music, TV, games, puzzles or pets.
- Check with the physical therapist about using heat or cold.
- Use pain medicine if ordered by doctor.

Urinary Tract Infection

- A urinary tract infection is a bladder infection. Medicine is needed.
- Call the doctor or nurse if you think your survivor has to urinate more often or has a burning feeling. Urine may smell strong or different.
- Call the doctor or nurse if your survivor becomes confused. Confusion can sometimes be a sign of urinary track infection.
- Encourage the survivor to drink lots of fluids. Water is best. Cranberry juice may also help.

Loss of bladder control (urinary incontinence)

- What is incontinence?
  - Doctors and nurses use this word to describe the uncontrolled loss of urine.
  - For stroke patients, incontinence may be caused when the brain and bladder do not communicate well.
  - Some medicines can cause loss of bladder control.
- How can I as a caregiver help with incontinence?
  - Talk about the problem with your survivor. Be sensitive to their feelings. Help to maintain their dignity as they struggle with incontinence.
  - Set up a regular toileting schedule, perhaps every 2 hours during the day.
  - A raised toilet seat may be useful.
    - Grab bars are helpful for getting off and on the toilet.
  - Keep the skin clean to avoid skin breakdown and sores.

- Use “incontinence products” only when absolutely necessary.
  - Pads, special underwear or adult diapers can be used if accidents occur between bathroom visits.
- Consider diet changes.
  - Some foods can irritate the bladder.
    - Citrus juices (like orange juice), spicy foods and artificial sweeteners may cause problems.
    - Caffeine, soda pop and alcohol may make the problem worse.
  - Drink enough fluids. Water is important. Strong urine can lead to bladder irritation. Increase fluids during the day, but cut down on the fluids at night.
- Night time concerns 
  - A bedside commode or urinal may be helpful.
  - Washable or throw away bed pads are useful at night. Try to avoid briefs or adult diapers at night to allow air to get to the skin.
  - Leave a night light on in the bathroom and hall.
  - A bell at the bedside can be used to call a caregiver for help.

- When do I need to contact a doctor or nurse about loss of bladder control?
  - If the above suggestions do not work, talk to your doctor or nurse. Sometimes medicines can help.

- Where do I find more information about incontinence?
  - Go to the website Medline Plus by the National Library of Medicine at: https://medlineplus.gov/urinaryincontinence.html
  - Go to the website by the National Institute of Diabetes and Digestive and Kidney Diseases at: https://www.niddk.nih.gov/health-information/urologic-diseases/bladder-control-problems or call: **1-800-860-8747**.

Constipation

- What is constipation?
  - A person is constipated when they have 3 or fewer bowel movements a week.
  - Your stroke survivor may complain of bloating or feeling full.
  - You may see small amounts of stool "leaking." You may find small, frequent "smears" on underpants.

- How can I as a caregiver help with constipation?
  - Serve a variety of high-fiber foods, especially beans, bran, whole grains, and fresh fruits and vegetables.
  - Encourage plenty of liquids. Survivors often forget to drink. A cool glass of water is best. Juices (prune, apple, etc.) are good choices as well. If you have diabetes, too much juice can raise your blood sugar. Include juices in the diet plan. Avoid caffeine, sodas, and alcohol.
  - Encourage daily exercise. Moving about is better than sitting still.
  - Don't ignore the urge "to go."
  - Allow for privacy in the bathroom.
  - Avoid regular laxative use. Ask the doctor about stool softeners and laxatives.

- When do I need to contact a doctor or nurse regarding constipation?
  - If there are swallowing problems, it may be hard to drink enough liquids. Check with the doctor or speech therapist.
  - Check with the doctor or nurse about medicines that may cause constipation.
  - Use laxatives or stool softeners only with the doctor or nurse's permission.
  - Call the doctor or nurse if the bowel movement is hard and difficult to pass.

- Where do I find more information about constipation?
  - Ask the doctor or nurse about how to avoid or treat constipation in your survivor.

- Go to the website MedlinePlus from the National Library of Medicine at: https://medlineplus.gov/constipation.html
- Go to the website by the National Institute of Diabetes and Digestive and Kidney Diseases at: https://medlineplus.gov/constipation.html or call this number**: 1-800-860-8747.**

Dizziness, Lightheadedness, or Balance Problems

- **What is dizziness?**
  - Dizziness is a feeling of lightheadedness, floating, or "wooziness."
  - There are several reasons your survivor may feel dizzy.
    - Medications
    - Not enough water or other fluids (dehydration)
    - Result of the stroke
    - Blood Pressure is too low
    - Other medical problem

- How can I as a caregiver help with dizziness?
  - Encourage your survivor to get up slowly from bed or from a chair.
  - Prompt your survivor to sit on the side of the bed for a few minutes before getting up.
  - Remind your survivor to drink enough fluids.

- When do I need to contact the doctor or nurse about dizziness?
  - Call your doctor or nurse if your survivor has dizziness but has not had it before.
  - Call your doctor or nurse if dizziness gets worse.
  - Call your doctor or nurse if your survivor faints or has a fall.

- **What about balance problems?**
  - As a result of the stroke, your survivor may be shaky on their feet.
  - Your survivor may also have trouble sitting up without help.
  - Falls can happen because of balance problems.

- How can I as a caregiver help with balance problems?
  - Learn about exercises from the physical and occupational therapists.
  - Have the survivor use a gait belt for you to grab on to while walking with the survivor.
  - Shoes need to be low heeled with rubber soles. They need to fit well.
  - Walk with your survivor on smooth ground. Remind him or her to use the walker or cane if needed.
  - Encourage good posture.
  - Check your house for things that could be tripped over. Get rid of loose rugs. Watch out for electrical cords or other things that can be tripped over.
  - Keep a sense of humor.
- When do I need to call the doctor or nurse?
  - Call if there is a fall.
  - Call if balance problems get worse.
- Where do I find out more information about dizziness or balance problems?
  - Talk with the physical therapist, doctor, or nurse.

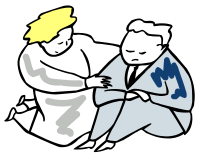
Feeling Tired or Fatigue

- What about fatigue? Fatigue is another word for feeling tired.
  - The stroke survivor may have less energy than before.
    - This can be because of medicine side effects, less exercise, or poor sleep. It may also be from over stimulation or too many things going on at once.
  - The stroke survivor may be using energy differently.
    - Little things, like dressing, take more energy.
    - Thinking takes more concentration.

  - Fatigue may be due to emotional changes.
    - Stroke may cause frustration, anxiety, anger and sadness.
    - Depressed feelings are common. Lack of energy goes along with a depressed mood.

- How can I as a caregiver help with fatigue?
  - Encourage survivor to talk with doctor or nurse about fatigue.
  - Celebrate little things.
  - Provide for rest periods and naps. Find a quiet place for them to nap.
  - Plan enjoyable activities every day.
  - Join your survivor for physical activity every day.

- When do I need to contact a doctor or nurse about fatigue?
  - Ask the doctor to "rule out" any other causes that might make your survivor feel tired.



Depression

- Many survivors feel depressed after a stroke. They may be depressed if they have:
  - Little interest or pleasure in doing things
  - No desire to see family or friends
  - Feeling down, depressed, or hopeless
  - Trouble falling or staying asleep
  - Poor appetite or overeating
  - Feeling bad about him or herself
  - Trouble concentrating
  - Moving or speaking slowly or being fidgety
  - Thoughts he or she would be better off dead

- Medications and counseling can help. Ask the doctor, nurse, or a psychologist about depression. Depression that is not treated can slow recovery. **See Tip Sheet #9 Dealing with the survivor's emotions** for tips on how to screen for depression and how to get help.

- **Call 911 or a crises line (24-hour Suicide Hotline: 1-800-273-8255, https://suicidepreventionlifeline.org/) if the survivor is planning on suicide (killing himself or herself).**

- **You can also call the hospital where the survivor receives care.**

What can I do as a caregiver to help with all of these special problems?

Be aware of the special problems that might come up. Check the ones below that you think might be a problem for your survivor:

____**Seizures** or partial seizures that can cause convulsions
____**Blood clots** in the legs or elsewhere in the body
____**Pneumonia** from fluid in the lungs or infection
____**Bedsores** from sitting or laying in one place too long
____**Limb contractures** - arm or leg becomes stiff and cannot move.
____**Shoulder pain** from lack of support or exercise of the arm
____**Other types of pain**
____**Urinary tract infection**
____**Loss of bladder control (urinary incontinence)**
____**Constipation**
____**Dizziness or Balance problems**
____**Feeling tired**
____**Depression**

Call for help if you notice any problems.

- **Call 911 if you notice:**
  - The warning signs of another stroke:
    - Sudden **numbness or weakness of the face, arm or leg,** especially on one side of the body
    - Sudden **confusion, trouble speaking or understanding**
    - Sudden trouble **seeing in one or both eyes**
    - Sudden trouble **walking, dizziness**, **loss of balance or coordination**
    - Sudden, **severe headache** with no known cause

Another way to recognize a stroke is BE FAST.

B- Balance – Loss of balance?
E- Eyes – Loss of vision in one or both eyes?

F- Facial drooping or numb? Ask the person to smile.
A- Arm weakness or numb? Ask the person to raise both arms.
S- Speech difficulty or slurred? Ask the person to say "The sky is blue."
T- Time to call 911. Note the time when symptoms first noticed, and the time when they were "last seen well."

- **Call 911 if you notice:**
  - Any seizures
  - Chest pain or discomfort that may be a heart attack
  - Trouble breathing

- **Call the doctor or nurse if you have any other questions.** They are there to help.

- Try to help the survivor be physically active. Doing prescribed exercises and being active helps to prevent:
  - **Blood clots** in the legs or elsewhere in the body
  - **Pneumonia** from fluid in the lungs or infection
  - **Bedsores** from sitting or lying in one place too long
  - **Limb contractures**
  - **Shoulder pain** from lack of support or exercise of the arm
  - **Constipation**
  - **Dizziness or balance problems**
  - **Feeling tired**
  - **Depression**

- Try to get the survivor to drink plenty of fluids. Drinking plenty of fluids helps to prevent:
  - **Pneumonia** from fluid in the lungs or infection
  - **Urinary tract infection**
  - **Loss of bladder control (urinary incontinence)**

    - **Constipation**
    - **Dizziness or balance problems**

- Try to help the survivor eat a healthy diet. Eating a healthy diet helps to prevent:
    - **Pneumonia** from fluid in the lungs or infection
    - **Bedsores** from sitting or lying in one place too long
    - **Constipation**
    - **Dizziness or Balance problems**
    - **Feeling tired**

Where can I find more information?

- Call the **American Stroke Association's Toll-Free Warmline 1-888-4-STROKE or 1-888-478-7653.** Also ask for a free subscription to Stroke Connection Magazine.

- Visit your local library to look for books on caregiving.

Recommended Books

Senelick, R.C. (2016). Living with Stroke: A Guide for Patients and Their Families (Fifth Edition). Birmingham: Healthsouth Press. ISBN 978-1891525186.

Jorgensen, L. (2021). The Caregiver's Guide to Stroke Recovery: Practical Advice for Caring for You and Your Loved One. Emeryville, California: Rockridge Press. ISBN 978-1-64876-577-3.