# **GUIDE**



# Clinical Guidelines for Medical Respite Care: Neurological Conditions

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# Introduction

Neurological conditions are those that impact the nervous system and have significant impacts on a person's overall health, functional abilities, and quality of life. Like other conditions, people experiencing homelessness are more likely to have certain neurological conditions, and the effects of these are worsened in the context of housing instability. People experiencing homelessness have been found to have higher rates of traumatic brain injury (TBI) and seizures and may be more at risk for cerebrovascular accidents (CVA) and neuropathy due to the difficulty in managing chronic conditions, such as cardiovascular disease and diabetes<sup>1,2,3,4</sup>. Neurological conditions can impact a person's cognition, which may be further exacerbated by environmental factors such as lack of sleep and safety, trauma, and co-occurring behavioral health disorders<sup>5,6</sup>. Neurological conditions, such as dementia and TBI, have been associated with increased hospital readmissions and may also cause a person to become or remain homeless due to the effects on cognitive and self-management skills<sup>3,7</sup>. People experiencing homelessness often have limited access to resources to address the impacts of a neurological condition, such as specialty care and rehabilitation services. Medical respite care provides a critical opportunity to engage with comprehensive health services, minimize impacts of neurological conditions, and work towards health stability. This document provides an overview of neurological conditions more common among people experiencing homelessness and guidance for medical respite programs to address these conditions.

# **Key Terms and Definitions**

<u>Cerebrovascular accident</u> (CVA; also known as a stroke) occurs when the blood supply to part of the brain is interrupted or reduced, preventing tissue from getting oxygen and nutrients. <u>Signs/symptoms</u> that someone is having a stroke include trouble speaking and understanding what others are saying, unilateral paralysis or numbness of the face, arms, or leg, problems with vision, sudden headache, and difficulty walking. A person is at higher risk of stroke if they have chronic conditions, such as heart disease or diabetes, or use substances and/or high amounts of alcohol.

<u>Dementia</u> is a general term for loss of memory, language, problem-solving, and other thinking abilities that are severe enough to interfere with daily life. There are five common forms of dementia including <u>Alzheimer's disease</u>, <u>Frontotemporal dementia</u>, <u>Lewy body dementia</u>, <u>Vascular dementia</u>, and mixed dementia.

<u>Harm Reduction</u>: A philosophical approach to medical care that extends beyond substance use and, in general, establishes individual agency and self-determination as central to any health intervention or efforts towards well-being. Harm reduction approaches call for the non-judgmental, non-coercive provision of services and resources to people experiencing homelessness to assist people in reducing harms related to chronic health conditions or health behaviors. Harm reduction-based care is collaborative, provides education on available interventions, and centers the goals of the individual in care planning.

<u>Headaches</u> are pain in any region of the head. Headaches can be caused by physiological factors such as chemical activity in the brain, muscles around the head and neck, the nerves or blood vessels around the skull, or by lifestyle factors such as stress, sleep, nutrition, alcohol use, and hydration. They may also be a symptom of an underlying illness or disease.

Migraines are headaches that can cause severe throbbing pain or a pulsing sensation, usually
on one side of the head. They are often accompanied by nausea, vomiting, and extreme
sensitivity to light and sound. Migraines can last for hours or days, with pain severe enough to
interrupt daily activities. Migraines can occur due to physiological and environmental factors.

<u>Meningitis</u> is an inflammation of the fluid and membranes surrounding the brain and spinal cord. Meningitis is most often caused by a viral infection, and symptoms include headache, fever, and a stiff neck. Individuals living in congregate settings are at higher risk for contracting meningitis.

**Neuropathy**, also known as peripheral neuropathy, results from damage to the peripheral nervous system (the system of nerves outside of the brain and spinal cord). Symptoms of neuropathy are most commonly felt in the limbs and include numbness, tingling, and weakness in the areas of the body affected. Neuropathy is often caused by another medical condition (such as diabetes) or an injury to the nerves.

<u>Seizures</u> are a sudden, uncontrolled electrical disturbance in the brain. They can cause changes in behavior, movements or feelings, and in levels of consciousness. There are several types and causes of seizures, and they can range in symptoms and severity. A seizure that lasts more than 5 minutes is considered a medical emergency.

- Epilepsy is a central nervous system (neurological) disorder in which brain activity becomes abnormal, causing seizures or periods of unusual behavior, sensations and sometimes loss of awareness. A diagnosis of epilepsy includes experiencing two or more seizures at least 24 hours apart that aren't brought on by an identifiable cause.
- Withdrawal seizures may occur after a person has abruptly stopped or significantly decreased
  their alcohol use after high alcohol consumption or has abruptly stopped use of
  benzodiazepines. Withdrawal may result in several symptoms, with seizures occurring within the
  first 12-48 hours after the reduction in alcohol or benzodiazepine intake. Withdrawal seizures
  may be misdiagnosed as epilepsy.

<u>Trauma Informed Care</u> (TIC): A patient-centered approach to care that recognizes the impacts of trauma and actively works to prevent re-traumatization and promote recovery. The principles of TIC are grounded in establishing a trusting relationship and a safe physical and psychological space in which to address needs.

<u>Traumatic brain injury</u> (TBI) is a form of acquired brain injury that occurs when a sudden trauma causes damage to the brain, such as a motor vehicle accident, assault, or fall. The severity of the TBI is determined by the length of loss of consciousness following the injury. Additional symptoms may include headache, confusion, lightheadedness, trouble with cognition, nausea, difficulty waking up from sleep, pupil dilation, slurred speech, and loss of coordination.

# Clinical Considerations

# **Background**

The causes of neurological conditions are diverse and dependent on the condition itself. However, certain risk factors can increase the onset of, or impact the recovery from, a condition (such as a TBI). Risk factors influencing the development of a neurological condition include:

- Genetics or congenital conditions
- Certain infections (such as meningitis or COVID-19)
- Decreased nutrition or malnutrition
- Physical injuries
- Those who use alcohol or substances are also at an increased risk of developing a neurological condition. It may be difficult to diagnose or determine if certain symptoms are caused by active substance use or a result of neurological condition.

Neurological conditions can be caused by physiological factors, however, risk and ability to manage conditions is impacted by environmental factors such as sleep, nutrition, and stress. People experiencing homelessness are more impacted by these factors and their ability to manage and reduce the impact of these circumstances can be inhibited.

- People experiencing homelessness have greater incidences of chronic conditions and environmental risk factors that increase likelihood of developing a neurological condition.
- Neurological conditions often have symptoms that are similar to other conditions, including
  various mental health diagnoses or intellectual disabilities, making it more difficult to diagnose
  unless there are supports or providers who are familiar with the person that can detect
  personality or behavior changes.
- People experiencing homelessness, living in poverty, and/or with a history of interpersonal violence have overall higher rates of brain injury and have less ability to access medical treatment once the injury has occurred.
- Management of neurological conditions can be difficult while homeless due to complicated medical regimens, required follow-up care (such as frequent blood draws), and decreased access to rehabilitation services that can address and improve ongoing symptoms.

Medical respite care can be an opportunity to:

- Establish a baseline of function and observe a person to identify if symptoms are caused by neurological conditions or other factors,
- Conduct evaluations and assessments to diagnose conditions,
- Minimize impact of unstable environments,
- Offer stability to implement health management activities,
- Engage in specialty care to manage conditions and symptoms, and
- Move towards housing to support overall health.

# **Assessment**

In all assessment processes, it is important to implement a <u>trauma-informed</u> and harm reduction-based approach, recognizing that people may not be ready to share their entire health history in the first encounter. A good history is key to creating an appropriate plan of care and can be built over several visits. Additionally, medical respite care can provide an opportunity to establish a baseline of function that can inform primary care providers and specialty providers and support monitoring of symptoms. A comprehensive assessment for neurological conditions includes the following:

### **Complete a History and Physical which includes:**

- Gather medical history as available and current prescribed medications
- Monitor for signs and symptoms of alcohol, benzodiazepine, or opiate withdrawal
- Family history
- Assess for cardiovascular risk factors for CVA
- Assess ability to follow medication regimens and instructions, and potential side effects of medications
- Assess for behavioral health (BH) disorders and substance use disorders by incorporating screening tools (PHQ9, GAD-7, DAST-10; ASI; SBIRT)
- Assess current cognitive status incorporating tools such as a Mini-Cog or Mini Mental Status
   Exam ©
- Assess global cognition using the <u>Montreal Cognitive Assessment (MoCA)©</u> or <u>St. Louis</u> <u>University Mental Status SLUMS</u>
- Assess balance and gait and history of fall risk
- Assess for vision and vision changes
- Assess <u>literacy</u>, <u>health literacy</u>, and <u>calculation skills</u>
- Assess and monitor for changes in personality or behavior
- Assess access to adequate nutrition and hydration
- Assess living conditions, current and where the person may discharge to, and supports available

## Cerebrovascular Accident (CVA) specific assessment includes:

- Assess extent of focal neurological deficit and determine time of onset
- Assess need for assistive devices for mobility
- <u>Assess ability to perform activities of daily living (ADL) independently and instrumental activities</u>
  of daily living (IADL) (this may require referral to physical and occupational therapy for full
  evaluation)
- Assess ability to communicate need and understand verbal and written information (this may require referral to speech and language pathology for full evaluation)
- Assess bowel and bladder continence and skin integrity

#### Dementia specific assessment includes:

- Use the <u>Medicare Wellness Exam</u> questions to determine specific indicators or risk factors for cognitive impairment
- Specific cognitive assessments for dementia
- Rule out possible delirium or other contributors to cognitive decline
- Assess impact on communication
- Assess impact on <u>daily function</u>
- Monitor progression of symptoms over time and assess for the need for a higher level of care:
  - This may include comprehensive assessment of ability to complete ADL, IADL, and communication skills

Note: Please also see the Clinical Guidelines for Medical Respite Care: Dementia for more in-depth information

#### Epilepsy or seizure disorder specific assessment includes:

- Assess for stability or current management (change in seizure frequency)
- Assess ability to follow medication regimen or any side effects that indicate a need to reevaluate the medication
  - Assess ability to engage in, and the need for, routine lab work to monitor blood levels of seizure medications (such as Dilantin)
- Assess for any injury that the patient may have sustained during seizure activity
- Screen for a history of traumatic brain injury (recent and lifetime)
- Assess for current substance use or medications that may increase seizure frequency:
  - Evaluate and assess if history of seizures is due to withdrawal and not a seizure disorder
  - Consider medication adjustments and discontinuing seizure medications if activity is related to substance withdrawal or if patient will continue to use substances or alcohol to minimize impact of conflicts with medications. (Note, providers may want to consult with neurology for medication changes)
    - Providers can instead consider medications such as gabapentin or Vivitrol to reduce seizure activity related to withdrawal

#### **Headaches and Migraines**

- Assess for frequency and severity
- Assess patient's awareness or knowledge of triggers to headaches/migraines
- Identify current medications or treatment (including over the counter medications)

# Peripheral Neuropathy specific assessment includes:

- Assess for the underlying illness or cause (diabetes, nutritional deficiency)
- Asses for stability of symptoms (rule out progression of symptoms)
- Assess for potential hazards (ulcers or burns from loss of sensitivity to touch)

# Traumatic Brain Injury specific assessment includes:

- Screen for a history of traumatic brain injury (recent and lifetime)
- Assess for post-concussive symptoms
- Assess for chronic and long-term impacts of previous head injuries, such as chronic migraines, vision changes, etc.
- Assess for impact on motor function, mobility, and ability to complete ADL
- Assess for impact on IADL

# Care Plan and Management

Strategies and treatment plans implemented should be person-centered, collaborative, and based on priorities and needs identified during the assessment process. As noted, interventions should be trauma-informed and integrate harm reduction principles to minimize risks and improve care. Providers can find more detailed guidance on assessment and intervention of specific neurological conditions in the *National Health Care for the Homeless Council Adapted Clinical Guidelines on Neurological Conditions*.

# **Person Specific Strategies**

Individual strategies for management of neurological conditions include:

- Referrals to rehabilitation providers to assess and develop skills and strategies for mobility, ADL, IADL, and communication.
- Provide space and technology needed to engage with telehealth providers and appointments.
- Provide <u>medication education</u> and <u>simplified instructions</u> for taking medications, complete medication reconciliation, simplify medication regimens as able, and establish with ongoing community supports as needed to <u>follow medication instructions</u>.
- Provide strategies to compensate for decreased cognition, including pillboxes or bubble/blister
  packs, calendars, using apps on phones (such as calendar, alarms, signing up for text reminders),
  signs that indicate the day/date, and lists of providers with names and pictures (as appropriate).
- Provide direct instructions or use the <u>teach-back method</u>. Repeat as necessary and manage provider frustration if patient is unable to remember information or takes several repetitions to learn.
- Ensure the patient has adequate time for self-expression to compensate for communication or language difficulties and avoid rushing during clinical/staff encounters if possible.
- Engage with behavioral health to address stress and provide support for managing changes related to diagnosis.
- Assess risk factors for meningitis and offer vaccine if indicated.

#### **CVA** specific considerations:

- Monitor vital signs for stability.
- Manage cardiovascular diagnoses.
- Provide education and support for health behavior related changes such as smoking reduction/cessation, dietary changes, and exercise.
- Educate on signs and symptoms of stroke recurrence.
- Address and provide referral, if needed, for management of vision and continence changes.

#### **Dementia specific considerations:**

- Provide external strategies to support decreased memory, including:
  - Writing down important information for the person to review later.
  - Setting alarms or calendar notifications, or text reminders for appointments.
  - o Taking pictures and writing simple lists of medical respite program staff.
  - Identifying a short list of key emergency contacts to keep in wallet or other easy to locate place.
- Limit new learning to essential information only.
- Dependent on progression of dementia, and if waiting for long-term care supports, the person may require assistance to complete more complex IADL such as:
  - Attending appointments.
  - Sorting and taking medications.
  - Managing money.
  - Completing complex paperwork.
- Note: Please also see the Clinical Guidelines for Medical Respite Care: Dementia for more indepth recommendations

### **Epilepsy or seizure disorder specific considerations:**

- Educate patient on and implement seizure precautions. In the MRC setting this may include:
  - Avoiding top bunks.
  - Using shower instead of bathtubs.
  - o Keeping walkways and area around bed clear.
  - Having a medical alert card, ID, or bracelet.
- Monitor any injuries sustained during seizure (mouth wounds, head injury).
- Notify the primary care provider of seizure activity.
- Educate/train nonclinical staff in seizure precautions.
- Educate patient regarding impact of substance use on seizures:
  - Safety precautions with substance use (e.g., not using alone).
  - Impact of use and decreasing use on seizure activity (e.g., withdrawal from alcohol).

# **Headache and Migraine specific considerations:**

- Support patient in developing a self-management plan to avoid or minimize exposure to triggers.
- Refer patient to neurology if current treatments are not effective.
- Advocate for the patient, if needed, to receive support or differing treatment of pain and discomfort related to headaches or migraines.

### **Peripheral Neuropathy specific considerations:**

- Address pain and provide pain management.
- Provide physical therapy and assistive devices as needed.
- Avoid trauma to affected areas (provide well fitted shoes, avoid friction and prolonged pressure, provide dry socks).
- Periodic foot checks.
- Notify primary care provider if any changes or variations occur.
- Educate patient regarding underlying cause and ways to avoid progression.
- Educate patient regarding ways to avoid secondary injury (e.g., daily visual foot inspections).

#### **TBI specific considerations:**

- Monitor for worsening of post-injury conditions or symptoms, such as worsening headaches, light and sound sensitivity, disorientation, etc.
- Support use of compensatory strategies for affected cognition, such as strategies for memory or attention.
- Provide space for rest and recovery with limited sensory input (darkened room, quiet space).
- Provide support to develop sleep routines and implement sleep hygiene strategies while in MRC.
- Provide education on risk for additional injury (such as interpersonal violence, substance use) and refer for additional supports as needed.
- Review comprehensive clinical recommendations for TBI in people experiencing homelessness.

# **Environmental Strategies**

- Ensure spaces are accessible and provide durable medical equipment as needed, especially for <u>ADL spaces</u>. Examples include shower chairs and grab bars for bathing, non-slip tread of bathmats, railings on hallways or beds, and easy to open door handles.
- Ensure walkways are well-lit to decrease fall risk and use nightlights or motion lights for bathrooms and hallways at night.
- Provide clear signage around the medical respite program to ease wayfinding and orient patients to the space. Signage should be easy to locate and within general eyesight.
- Provide <u>written instructions</u>, reminders, and use consistent schedules to support patients with decreased memory and attention due to cognitive changes.
- Offer spaces with varying intensities of light and allow patients to have space where they can
  rest without substantial noise or bright lights. Offer ear plugs or eye covers if unable to change
  or control lighting and noise.

# Referrals

- Behavioral health: to address impacts of changes in function related to neurological condition, or to address substance and alcohol use if person desires to decrease use.
- Gerontology or Geriatric Psychiatry: for assessment and referral of conditions related to older age (such as dementia). Consider referring patients if presenting with conditions related to aging even if younger than 60.
- Neurology: for diagnosis and ongoing management of neurological conditions.
- Neuropsychiatry: for assessment of cognition/cognitive function and impact of neurological conditions.
- Occupational Therapy: evaluation to identify underlying factors and impact of neurological conditions and environmental barriers on ADL and IADL performance.
- Physical Therapy: evaluation to identify underlying physiological factors and impact of neurological conditions and mobility (including gait, balance, and motor skills).
- Speech and Language Therapy: evaluation to identify impact of neurological conditions on communication and speech.

# **Discharge Planning**

Patients with neurological conditions may be ready for discharge from medical respite care when:

- Symptoms are stable and medications no longer need to be adjusted.
- The patient is able to independently manage medication regimens or has support to manage medications.
- Patient has adequate supply of medications.
- Patient is connected with, and able to independently go to, specialist appointments, or supports are in place to facilitate attending appointments.
- Patient has completed interventions with PT, OT, or speech therapy, or is able to attend appointments independently.
- Patient has completed needed diagnostic and follow-up testing.
- Patients with cognitive impairment are connected to intensive ongoing community supports, such as intensive case management or local <u>Home and Community Based Services</u>.
- Patient is transitioning directly into higher level of care as determined by need.

# Advanced Training and Advocacy

- Training for staff to respond to and address neurological events such as <u>seizures</u> or <u>stroke</u>.
- Advocacy for accessible and affordable housing and community-based supports for individuals
  with cognitive impairment and/or mobility needs to live safely within the community.
- Inclusion of individuals experiencing homelessness within Home and Community Based waiver programs to receive long-term care supports within the community, regardless of housing status.
- Advocacy for individuals to more easily access higher <u>levels of care</u> when needed.
- Training and education for staff regarding management of cognitive impairment and dementia.

# Case Example 1

**Background:** Gary (he/him/his) is 54 years old and was recently admitted to the hospital following a cerebrovascular accident (CVA/ stroke). Gary worked exclusively in construction most of his adult life. Prior to hospitalization, Gary maintained his own apartment and had a limited social support network, primarily spending time with coworkers. Due to the intensity of his work schedule, he had limited time to engage in primary care to address existing cardiovascular conditions. The stroke resulted in Gary experiencing aphasia and right-sided hemiparesis with significant weakness.

Gary was transitioned from the hospital to a skilled nursing facility (SNF) for rehabilitation. During his stay at the SNF Gary lost his apartment because he was unable to pay rent due to a lack of working and income. Gary's insurance enrollment also lapsed, resulting in the SNF expediting his discharge plan. However, within the SNF Gary was able to make significant functional gains including:

- Ambulating safely with use of a quad cane;
- Increased ability to complete ADL when using durable medical equipment and adaptive devices;
- Increased use of strategies to communicate needs and manage frustration with limited communication skills.

Gary was referred to the medical respite program due to his new homelessness status, his need for ongoing supports to establish resources and ongoing health care, and to continue recuperating from the CVA. The SNF social work team was concerned about his ability to function within a typical shelter setting and identified the increased structure and support of medical respite care would be most appropriate.

After admission to the medical respite program Gary demonstrated some difficulty engaging with staff and the setting due to his communication issues and adjustment to homelessness status. However, Gary was engaged in care and able to work with the team to identify goals.

**Assessment:** Gary engaged with the medical respite program nursing and case management staff to identify care plan goals. Gary identified several goals regarding social needs (housing, income, benefits). Additionally, he identified concerns about taking medications, as he had not previously had to manage medications prior to his stroke or while at the SNF. Gary stated he felt lonely due to his circumstances. He declined a behavioral health referral, but was interested in finding his family who lived locally but with whom he had lost contact.

Intervention: Gary was connected with a local health center for ongoing primary care. His medical providers completed medication reconciliation and adjusted his medications for a simplified regiment that would be easier to follow independently. The nursing staff provided education to Gary regarding his medication, dosing schedules, and supported Gary as he transitioned to managing his medications independently. The case manager was able to work with Gary on his other priorities, including reenrolling in health insurance, coordinating appointments for outpatient OT, PT, and speech therapy, and navigating potential housing options. The case manager also worked with Gary to reconnect with family, including his nephew who lived nearby. Gary was also supported in applying for Social Security benefits, as he was not going to be able to return to construction work.

**Outcomes:** Gary was able to reconnect with his nephew who offered to have Gary live with him for ongoing support. Gary was transitioned to a community-based case manager to support him in navigating and completing the Social Security benefits process. Gary was also connected with the local transportation unit that provided rides for individuals with disabilities at a lower cost, enabling him to continue attending outpatient appointments.

# Case Example 2

**Background:** Gabby (she/her/hers) is 32 years old and was brought into the emergency department (ED) by ambulance after experiencing a seizure where she fell and hit her head on the sidewalk. Her seizure was witnessed by others in the community who called 911. Gabby has a history of multiple ED visits for seizure activity. Gabby has a 5-year history of housing instability, in which she has stayed with others she knows or on the street. She was referred to the medical respite program for stabilization and monitoring of seizure activity, and to engage more intensively with neurology.

After admission to the medical respite program Gabby identified the benefit from being able to engage more regularly with health care providers, noting that the seizure activity was "scary." Gabby was observed to have contentious phone calls with others in the community, after which she was often seen to be upset and/or crying.

Assessment: Due to Gabby's recent head injury as a result of the seizure, the medical respite nurse screened for a history of TBI. The screening resulted in positive identification of a significant TBI history, which included a car accident as a teen where she was unconscious for several hours, and a history of interpersonal violence over the past 10 years. Gabby was also screened for a history of alcohol use, which revealed periods of heavy drinking (most often when staying with family) followed by no alcohol use (when staying on the street). Gabby identified she was unsure of completely stopping all alcohol use but expressed interest in decreasing intake. Due to her frequent seizures and TBI history, Gabby was also screened by occupational therapy regarding cognitive and functional skills. The cognitive assessment identified Gabby had overall decreased cognition, especially in the areas of attention and memory, and had difficulty remembering to take medications and medication schedules. She also had difficulty keeping track of community case managers and which services she has accessed in the past (e.g., could not remember if she had completed the coordinated entry process).

Intervention: While at the medical respite program Gabby's medical team worked with neurology to simplify her medication regimen and monitored for seizure activity. She was encouraged to report any alcohol use to further identify potential triggers for seizure activity and to reduce impacts of potential detoxification. She received ongoing education on how to monitor her activities to identify potential triggers of seizures and to notice early signs/symptoms to increase safety. The OT and nursing staff supported Gabby in identifying and using strategies for medication management, which included using a pillbox and keeping it by her ADL supplies to remind her to take them. The case manager referred Gabby to the local brain injury association to identify potential supports and resources she may be eligible for. Gabby also completed an assessment with the medical respite behavioral health consultant who identified significant ongoing interpersonal violence with family, which was often a precursor to increased alcohol use and needing to stay outside. With her care team, Gabby was able to identify how the significant trauma, alcohol use, and history of TBI connected to her frequency of seizures.

**Outcomes:** Gabby was referred and accepted into a transitional housing program for survivors of interpersonal violence. The program supported Gabby in identifying long-term housing resources and meeting additional goals. The case manager at the program also supported Gabby in following-up with the brain injury association to access available resources. Gabby was able to complete a full neurology work-up, and medications were able to be adjusted as her seizure activity was minimal in the context of the stability of medical respite and without additional alcohol use. Gabby was agreeable to a Vivitrol injection to manage alcohol cravings and reduce use. She was able to continue to use her pillbox for ongoing medication management and planned to continue behavioral health care through the transitional housing program.

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