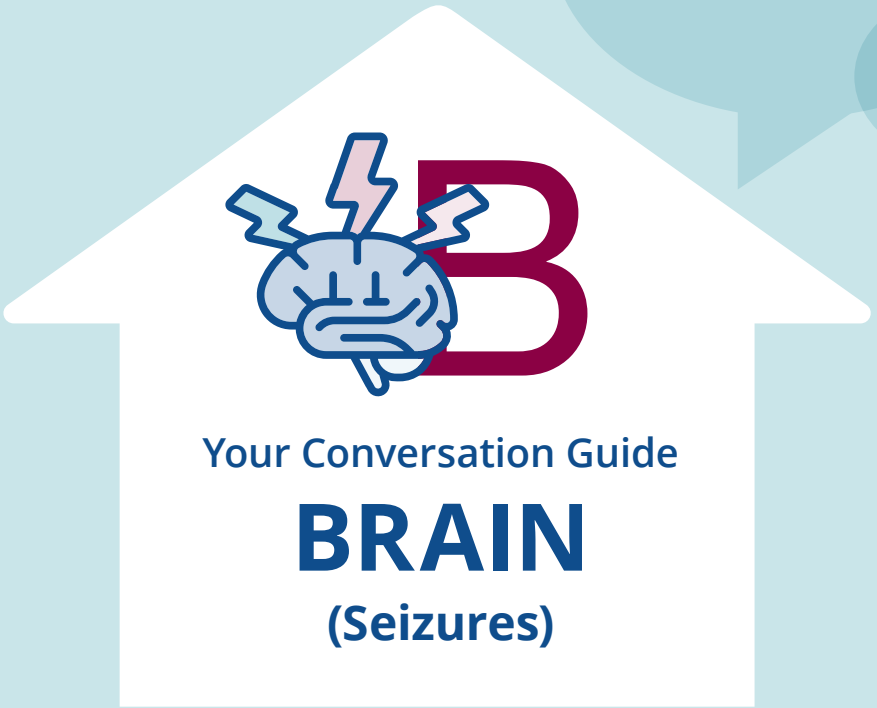
Be Prepared:
Palliative Care Emergencies in the Home

Navigating Home Emergencies with Care and Compassion



Your Conversation Guide

BRAIN

(Seizures)

Canadian Home Care Association

CONTRIBUTORS

Angelevski, Elizabeth, *Director of Projects and Knowledge Translation, Canadian Home Care Association*

Campagnolo, Jennifer, *Palliative Care ECHO Project Lead, Canadian Home Care Association*

Hall, Audrey-Jane, RN, *Assistant Director General and Director of Palliative Care, Society of Palliative Home Care for Greater Montreal Region*

Iancu, Andrea, MD, PhD, CCFP(PC), FCFP, T*eresa Dellar Palliative Care Residence, West Island Montreal CIUSS and Palliative Home Care*

McAlister, Marg, *Priority Projects Consultant, Canadian Home Care Association*

Mehta, Anita, RN, PhD, CFT, *Director of Education and Knowledge Exchange, Teresa Dellar Palliative Care Residence*

SOURCES

- Baker Rogers, J., Modi, P., Minteer, J.F. Dyspnea in Palliative Care. [Updated 2022 May 1]. In: StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing; 2023 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK526122/
- Fisher RS, Cross JH, French JA, et al. Operational classification of seizure types by the International League Against Epilepsy: Position paper of the ILAE Commission for Classification and Terminology. Epilepsia 2017.
- Kälviäinen, R., & Reinikainen, M. (2019). Management of prolonged epileptic seizures and status epilepticus in palliative care patients. *Epilepsy & Behavior : E&b*, *101*(Pt B), 106288–106288. https://doi.org/10.1016/j.yebeh.2019.04.041
- Kälviäinen, R., Allal, Z., & Kantanen, A.-M. (2023). When is it time for palliative and end-of-life care in status epilepticus? *Epilepsy & Behavior*, *141*. https://doi.org/10.1016/j.yebeh.2022.109058
- Rautureau, P. (2016). L'urgence, la fin de vie et le domicile : de l'improvisation à la coordination. *Jusqu'à la mort accompagner la vie*, 127, 99-110. https://doi.org/10.3917/jalmalv.127.0099
- Sharma, A., Besbris, J. M., Kramer, N. M., Daly, F. N., Singhal, D., Jones, C. A., & Mehta, A. K. (2021). Top ten tips palliative care clinicians should know about seizures at the end of life. *Journal of Palliative Medicine*, *24*(5), 760–766. https://doi.org/10.1089/jpm.2021.0096
- The Pallium Palliative Pocketbook: a peer-reviewed, referenced resource. 2nd Cdn ed. Ottawa, Canada: Pallium Canada, 2022.
- Tradounsky, G. (2013). Seizures in palliative care. *Canadian Family Physician Medecin De Famille Canadien*, *59*(9), 951–5.
- Vecht CJ, Wagner GL, & Wilms EB. (2003). Interactions between antiepileptic and chemotherapeutic drugs. The Lancet Neurology, 2(7), 404-409.
- https://www.mariecurie.org.uk/professionals/palliative-care-knowledge-zone/recognising-emergencies/recognising-emergencies
- https://www.ncbi.nlm.nih.gov/books/NBK526122/

WHO WE ARE

Established in 1990, the Canadian Home Care Association (CHCA) is a national non-profit membership association dedicated to advancing excellence in home and community care. Our eiCOMPASS Project aims to empower home care providers to deliver emotionally intuitive, competency-based palliative care. We are enhancing the skills of frontline providers and improving team-based care that is compassionate, responsive, and person- and family-centred.

CHCA Website / X / LinkedIn

The production of this material has been made possible through a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

Be Prepared:
Palliative Care Emergencies in the Home

Navigating Home Emergencies with Care and Compassion

This Conversation Guide is designed to help you, as the healthcare provider, have compassionate and effective conversations with patients, their caregivers, and families on how to manage a palliative care emergency at home.

Palliative Care Emergencies in the Home

Unexpected clinical changes can arise suddenly in patients receiving palliative and end-of-life care at home. These unforeseen events, often referred to as palliative care emergencies, might lead to an unplanned visit to the emergency department. According to the Canadian Institute for Health Information (2023), almost 1 in 4 patients receiving palliative home care were transferred to hospital at the very end of life.

Palliative care emergencies can significantly impact a patient's remaining quality of life and be deeply distressing for their caregivers. As a provider of home-based palliative care, it's crucial for you to recognize patients who are at risk and engage in clear, concise conversations with them and their caregivers. This empowers and equips them to manage emergencies while awaiting assistance from the palliative care team.

In response to requests from home-based palliative care providers, the Canadian Home Care Association (CHCA) has developed six Conversation Guides. Each guide addresses a palliative care emergency commonly experienced at home. The series, titled "Be Prepared: Palliative Care Emergencies in the Home", uses a simple memory key to easily identify and remember the following emergencies:

- Breathing (dyspnea)
- Balance (hypercalcemia)
- Bleeding (massive hemorrhages)
- Brain (seizures)
- Bones (spinal cord compression)
- Blockage (superior vena cava obstruction)

This Conversation Guide focuses on the BRAIN (seizures).

Using the term "emergency" in palliative care discussions, despite initial alarm, is crucial for preparing both caregivers and patients with essential information and actions to respond effectively to critical situations, ultimately improving patient care.

How the Conversation Guides work

Embarking on difficult conversations about palliative care requires a nuanced approach, encompassing not just the clinical aspects, but also the emotional and practical actions to empower caregivers and patients. Here's what to expect in each guide:

A Holistic Approach

The "Head-Heart-Hands" approach provides a comprehensive framework for palliative care discussions. Given the profound challenges patients and caregivers face, including serious illnesses and emotionally charged decisions, this three-pronged approach ensures conversations are thorough and compassionate.

Head (Think): This cognitive component focuses on delivering clear information and dispelling misconceptions about illnesses and/or interventions. An informed patient or caregiver can make educated decisions, reducing uncertainties and alleviating fears.

Heart (Feel): Emotion is intrinsic to palliative care. Beyond physical symptoms, it's about addressing the emotional strains of serious illness. Using Emotional Intelligence (EI), you ensure patients and caregivers feel acknowledged and supported. This is about validating emotions, showing empathy, actively listening, and offering comfort.

Hands (Do): This actionable aspect provides patients and caregivers with concrete steps. Understanding and emotional support are pivotal, but knowing the tangible actions to take is crucial. Clear directions bolster confidence and competence in patients and their caregivers.

A Practical Tool

Each of the six Conversation Guides is structured into three distinct sections:

1 A Conversation Checklist

This is your blueprint for navigating challenging discussions about palliative care emergencies. It offers actionable advice on how to ready yourself for the conversation, relay clinical knowledge using the "Head-Heart-Hands" approach, and foster trust through key emotional intelligence techniques, such as empathy and active listening.

2 Details about the Palliative Care Emergency

In the "Palliative Care Emergency" section, you'll learn about the condition's intricacies, uncovering its underlying mechanisms, prominent signs and symptoms, and associated risk factors. You'll also find tailored conversation pointers for engaging both patients and caregivers. Additionally, you'll get a straightforward breakdown of potential treatment options and care solutions, enabling you to explain to patients and/or caregivers how to manage the situation, effectively and safely, at home.

3 A Tool for Patients and Caregivers

Equip patients and caregivers with a variety of techniques and actions to manage potential emergencies at home. This section also offers tips on how you can communicate this crucial information effectively. Designed for utility, this segment is meant to be left behind in the home, granting patients and caregivers immediate access to both the information and helpful diagrams, whenever necessary.

Furthermore, with guided prompts and questions, you'll be primed to structure your dialogue, gauge concerns, and offer clarity. It's imperative to remain attuned to the patient's care goals, especially during emergencies, to guarantee that proposed strategies align with their goals of care and life expectancy.

1

A Conversation about the BRAIN (Seizures)

Discussing the potential risk for seizures with patients and their caregivers in home-based palliative care is crucial for informed decision-making and preparedness. While the term "emergency" highlights the gravity of the situation, you can frame it in a way that doesn't cause alarm but encourages proactive planning.

With this Conversation Guide, you're better prepared to facilitate reassuring discussions on managing such emergencies at home. These situations require your dual expertise: connecting genuinely with patients and their families using emotional intelligence and clinical knowledge.

A Conversation Checklist

This checklist provides actionable steps to ready yourself for difficult conversations, to share clinical insights through the "Head-Heart-Hands" lens, and cultivate trust using emotional intelligence skills, like empathy and active listening.

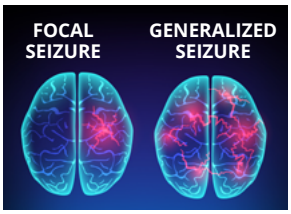
What to include in your conversation	Helpful phrases for Nurses
Start with the following: a) Introduce the **purpose** and **importance** of having the conversation with empathy.	**PURPOSE/IMPORTANCE:** *"I appreciate that you may be facing some challenges. It's important that we talk about some of the situations that could happen at home so that you know how to manage them."* *"It is really important to have this conversation with you because this information will help you understand what is happening and how to manage in the moment or get help."*
b) Assess their **readiness** to have the conversation with sensitivity (i.e., ask for permission).	**READINESS:** *"We need to talk about your ability to recognize the signs of a seizure and when it is time to get help. When do you think would be a good time to talk about it?"*
c) Ask about their **fears and/or worries** and actively listen to their response(s).	**FEARS/WORRIES:** *"I'm genuinely interested in understanding your concerns. Can you share some of them with me?"* *"I want to make sure you feel you have the support you need. Is there anything about caring for (person's name) that worries or scares you?"*

What to include in your conversation	Helpful phrases for Nurses
Describe what a seizure is and provide information on what they might see and/or hear, how they may feel, and what they can do	*"A seizure can be scary, but understanding its signs or symptoms can give you some peace of mind. Let's talk about what you might hear or see."* *"I realize that witnessing a loved one struggle can be frightening. Let's talk about how it might feel and ways to cope."* *"Having a better understanding of what is happening can help you feel more prepared if it happens. These are some really easy hands-on things you can do to help make the situation better."*
Provide reassurance and offer genuine hope	*"I know this may seem difficult for you, but I know you can do this. By working on this together, we will help you feel prepared."*
Encourage reflection, validate their feelings, and ask them to share what they have heard and/or understood	*"What you feel and think matters. Would you like to tell me how this is making you feel or what you are thinking about at the moment?"* *"Do we need to take a minute to go over anything we've just spoken about? Is there anything I've said that you are unsure about or isn't clear?"* *"How are you feeling about this information so far? Please let me know if anything feels overwhelming or unclear."*
Be observant of non-verbal cues and respond with compassion	*"Something seems to have (upset/worried/saddened) you. Would you like to talk about it?"*
Reiterate support with warmth and connection	*"Remember, you're not alone in this. Our team is here to guide, support, and answer any questions you might have."*
Wrap-up the conversation	*"Thank you for sharing your thoughts and feelings with me. Remember, our team is here to provide the care and support you need."*
Document the discussion to help the interdisciplinary healthcare team identify areas needing attention	*"I'll write down our talk and share it with the healthcare team, so that everyone is on the same page and we all work together."*

2

Seizures, in the context of palliative care, can significantly reduce the patient's quality of life. In a survey, up to 75% of patients and caregivers reported moderate to severe distress following a seizure episode, emphasizing the need for effective management strategies and appropriate support (Wagner et al. 2003).

The Palliative Care Emergency–BRAIN (Seizures)



What is a Seizure?

Information for Nurses

Seizures result from sudden, uncontrolled bursts of electrical activity in the brain, leading to abnormal muscle movements, altered consciousness, and unusual behaviours or emotions. They're caused when affected brain neurons send abnormal signals to nearby neurons, disrupting their activity. The type of seizure varies based on its origin in the brain and the extent of its spread.

A seizure lasting longer than five minutes is an emergency. Status epilepticus is seizure activity (convulsive or nonconvulsive) lasting longer than 30 minutes.

How to describe a seizure to Patients and/or Caregivers

"A seizure occurs when there's a sudden surge of electrical activity in the brain. It can affect specific areas or larger portions of the brain. The type of seizure and the symptoms you might observe or experience depends on which area(s) of the brain is/are affected by this electrical burst."

Who may be at risk?

Information for Nurses

Patients with primary or metastatic brain tumours, or those with a history of seizures, are more likely to experience seizures towards the end of life. Additionally, patients may be at risk due to cerebrovascular diseases (e.g., stroke) or biochemical abnormalities, such as low sodium or high calcium levels.

How to describe who may be at risk to Patients and/or Caregivers

"Individuals with brain tumours, a history of seizures, or specific conditions affecting the brain, like Parkinson's or Alzheimer's Disease, as well as those with imbalances in the body's chemistry like diabetes or thyroid disorders, might be at risk for seizures. Additionally, certain medications can trigger seizures. Being aware of these risks helps in staying prepared. "

Pathophysiology

Information for Nurses

Seizures are the result of abnormal electrical activity in the brain. They can be categorized based on where they begin and how they manifest:

Focal onset seizures:

- Origin: Start in a specific region of the brain.
- Progression: Can remain localized or spread across the brain.
- Consciousness: Can be retained or impaired. When impaired, these were formerly termed complex partial seizures. These are the most common seizures in adults and may be the type you see most often in people living with a terminal illness.
- Symptoms: Depend on the brain area affected.
- Motor symptoms include repetitive actions like lip-smacking or varied muscle movements such as clonic (jerking or twitching movements), tonic (muscles become rigid), and atonic (suddenly go limp) movements.
- Non-motor symptoms range from odd sensations or emotions to experiencing unusual smells or tastes.
- Presentation: Individuals may seem awake but unresponsive, may not interact normally, or might engage in repetitive behaviours.

Generalized onset seizures:

- Origin: Begin simultaneously in both hemispheres of the brain.
- Types: Divided into motor (convulsive) and non-motor (absence) seizures.
- Motor (Convulsive): The tonic-clonic or grand mal seizure is a well-known example, characterized by muscle stiffening (tonic phase) followed by twitching (clonic phase).
- Non-Motor (Absence): Brief lapses of consciousness without muscle movements.

Seizures, whether focal or generalized, can be triggered by various underlying causes.

- Progression of underlying brain lesions: For patients with primary brain tumours, or metastases to the brain from other cancer sites (e.g., breast or lung cancer), the progression of these lesions is a frequent cause of seizures.
- Structural damage to the brain: Brain tumours, hemorrhages, and metastases associated with some serious illnesses (e.g., cancer, Alzheimer's Disease, or stroke) can often lead to seizures.
- Systemic and metabolic influences: Relevant in patients with multi-organ system failures, as toxins accumulate in the blood and can induce seizures. Metabolic abnormalities, such as hypoglycemia or hyperglycemia, can arise from disorders like diabetes or pancreatitis.
- Medications: Some serious illnesses require medications that can lower the seizure threshold or have seizures as a side effect (e.g., antipsychotics or antibiotics, like imipenem) or be caused by withdrawal from drug and/or alcohol misuse.
- Abnormal chemical activity in the brain: Imbalances in neurotransmitters or their receptors can trigger seizures (e.g., in Epilepsy or traumatic brain injury).

How to explain what causes a seizure to Patients and/or Caregivers

"Seizures happen when there is abnormal brain electrical activity. They can start in a specific brain area or both sides of the brain at once. Seizures can be caused by many different things and depend on a person's illness. Some common triggers are brain tumours, organ failure, metabolic or chemical imbalances, or medications."

Signs and Symptoms

Information for Nurses

What you may see will depend on the type of seizure the patient is having:

Aura: Often considered a warning sign or the beginning of a seizure. Not everyone experiences an aura.

- Flashing lights or patterns
- Smells or tastes that aren't really there
- Sudden feelings of fear, anxiety, or happiness
- Feelings of unease or anxiety
- Deja vu or jamais vu sensations
- Visual or auditory disturbances

Focal seizures with awareness	Focal seizures with loss of awareness	Generalized seizures
• Sudden, jerky movements of one limb or side of the body • Numbness or tingling sensations • Hallucinations involving any sense • Abdominal discomfort or rising sensation in the stomach	• Eye roll or staring at a fixed point • Repetitive movements such as lip-smacking, picking at clothes, or aimless wandering • Sudden stop in motion or conversation • Confusion or dazed state • No recall of the episode	• **Tonic-clonic seizures (previously grand mal seizures)**: Sudden loss of consciousness - Body stiffening (tonic phase) followed by rhythmic jerking (clonic phase) - Possible incontinence (loss of bladder/bowel control) - Postictal confusion and fatigue • **Absence seizures (previously petit mal seizures):** Brief episodes of staring or blanking out - Rapid blinking or chewing motions - No memory of the episode • **Tonic seizures:** Sudden muscle stiffness or rigidity, especially in the back, arms, and legs - May fall if standing when the seizure starts • **Atonic seizures (drop attacks):** Sudden loss of muscle tone, leading to collapse or falling down - Brief duration, typically seconds • **Myoclonic seizures:** Sudden, brief jerks or twitches of a muscle or group of muscles

Postictal phase: After a seizure, especially after tonic-clonic seizures: Confusion or disorientation; Fatigue or drowsiness; Memory gaps; Headache or body aches.

What to say about signs of a seizure to Patients and/or Caregivers

"Seizures can show themselves in different ways. Here's what to look for:

- *Early Warning Signs: A person might feel uneasy, experience unusual smells or tastes, or have sensations of deja vu.*
- *Sudden Movements: The individual may have jerky movements in one limb or part of the body, or the entire body might stiffen and then jerk rhythmically.*
- *Staring and Repetition: The individual might stare blankly and might not respond to you. They could repeat certain actions, like lip-smacking or picking at clothes.*
- *Loss of Consciousness: Some seizures can cause a person to blackout or lose consciousness, sometimes leading to a fall.*
- *Brief Blank Spells: These are short episodes where someone seems to 'zone out' for a few seconds. It may look like they're daydreaming, but they won't remember it.*
- *After the Seizure: Once the seizure ends, the person might feel confused, tired, or have a headache. They might not remember the seizure at all."*

Treatment Options

Information for Nurses

Managing a pre-existing seizure condition becomes more challenging when someone has a terminal illness. This challenge might arise because medications used to treat other symptoms, or the symptoms themselves, increase the risk of seizures.

It's also essential to determine if other factors might be influencing seizure activity. Lack of sleep, drug use, alcohol misuse, or medication nonadherence can all be potential triggers for seizures. For those who may become unable to take anti-seizure medications orally, abruptly stopping anticonvulsant medications can increase the risk of seizures or status epilepticus. Therefore, alternative routes for administering these medications should be considered.

Some people may take regular medication, such as carbamazepine or levetiracetam, to prevent seizures. The type of medication will depend on what's causing the seizures and on any other drugs someone is taking.

Treating acute seizures:
Most seizures are self-limiting; however, if the seizure lasts longer than 2 minutes, or if the person has multiple seizures and does not recover consciousness between seizures, they require rapid treatment to end the seizures (seizure rescue plan). The medication of choice is a benzodiazepine, ideally administered within five minutes of onset. Benzodiazepines may be administered through a variety of routes including: subcutaneous, buccal, intranasal, and rectal. Midazolam and lorazepam are the most frequently used. Diazepam is an alternative. If benzodiazepines don't work, phenobarbital may be prescribed.

What to say about treatment options to Patients and/or Caregivers

"Most seizures end on their own. However, if a seizure is long (over 2 minutes) or if there are multiple seizures without waking up in between, we need to take action. We can teach you to administer emergency medications (e.g., midazolam, lorazepam, and diazepam). These can be given in various ways, such as under the skin, in the cheek, through the nose, or rectally.

"The most important thing is to stay calm. Make sure they are safe and as comfortable as possible. If the person is conscious, reassure them. We will set up a 'seizure rescue and response plan' so everyone knows what to do and you will be prepared if a seizure happens."

Be Prepared: Palliative Care Emergencies in the Home

A Tool for Patients and Caregivers

Your Conversation Guide
BRAIN
(Seizures)

This tool helps you know the actions you can take and reassuring words to use if your loved one is experiencing a seizure. Your healthcare provider will review the actions with you.

Actions you can take	Comforting Words
Be aware It is important that you pay attention to what time the seizure starts and how long it lasts. See if you can remember if there was anything unusual before the seizure started.	*"Did you notice anything unusual or different before you had the seizure?"*
Stay calm, ensure safety and comfort • Place something soft under their head and loosen any clothing they may have around their neck. • If you notice blood or vomit (from the nose or mouth), place the patient in the recovery position (turn the person on their side), if possible, so they don't choke	*"I'm here with you. I will not be leaving."* *"I am turning you on your side to keep you safe."* *"I am going to make sure you are comfortable."*
Medications If prescribed, administer dosage (only if you were shown how to do so)	*"This medication will help you. The nurse has shown me how to administer it."*
Observe The patient may sleep for awhile after a seizure. Keep observing the patient after the seizure in case another seizure occurs.	*If the patient wakes up, ask how they are feeling:* *"Tell me how you feel now" or "Did you feel anything similar to what you felt last time before you had a seizure?"*

Do NOT restrain movement: Holding the person down or trying to stop their movements can cause injury. Instead, clear the area around them of any sharp or hard objects to prevent harm.

Do NOT put anything in their mouth: Placing something in a patient's mouth will cause damage to the teeth or jaw or cause other injury. There is no risk of swallowing their tongue. Don't try to get them to drink or swallow.

Do NOT attempt to move the person (unless in immediate danger): Only move them if they are in a dangerous location, like near fire or on a busy road. Otherwise, wait until the seizure is over to reposition or move them.

Do NOT block airway: Do not put them on their back. Instead, turn them on their side (recovery position) to keep their airway clear unless there's a spine or neck injury risk.

Do NOT leave them alone: Always stay with the person until the seizure is over and they regain full consciousness. After a seizure, there's often confusion, and the person may not know where they are or remember the seizure.

IF:

- ✓ you feel overwhelmed and need help.
- ✓ you feel your loved one is not feeling better after trying different strategies.
- ✓ you are worried about a brain seizure.
- ✓ you have questions about what to do.

Call your Healthcare Team

Day time: _____

Evening: _____

Night time: _____

Canadian Home Care Association

YOUR LOGO HERE

5 things you should know about Seizures

1 What is a seizure?

A seizure occurs when there's sudden bursts of electrical activity in the brain. It can affect specific areas or larger portions of the brain. The type of seizure and the symptoms you might observe or experience depends on which area(s) of the brain is/are affected by this electrical burst.

2 What causes a seizure?

Seizures happen when there is abnormal brain electrical activity. They can start in a specific brain area or both sides of the brain at once.

Seizures can be caused by many different things and depend on a person's illness. Some common triggers are brain tumours, organ failure, metabolic or chemical imbalances, or medications.

3 What signs should I look for?

Seizures can show themselves in different ways. Here's what to look for:

- **Early warning signs:** A person might feel uneasy, experience unusual smells or tastes, or have sensations of deja vu.
- **Sudden movements:** The individual may have jerky movements in one limb or part of the body, or the entire body might stiffen and then jerk rhythmically.
- **Staring and repetition:** The individual might stare blankly and might not respond to you. They could repeat certain actions, like lip-smacking or picking at clothes.
- **Loss of consciousness**: Some seizures can cause a person to blackout or lose consciousness, sometimes leading to a fall.
- **Brief blank spells**: These are short episodes where someone seems to 'zone out' for a few seconds. It may look like they're daydreaming, but they won't remember it.
- After the Seizure: Once the seizure ends, the person might feel confused, tired, or have a headache. They might not remember the seizure at all.

4 How can we treat a seizure?

The most important thing is to stay calm. Make sure the person is safe and as comfortable as possible. If the person is conscious, reassure them. Your healthcare team will set up a 'seizure rescue and response plan' to help you be prepared if a seizure happens.

5 When should I call the healthcare team?

Always know your healthcare team is available to support you. Some specific situations when you should urgently contact the healthcare team if a person has a seizure are:

- **First-time seizure:** If the person has never had a seizure before, it's crucial to seek medical evaluation to determine the cause and appropriate care.
- **Difficulty breathing:** After the seizure ends, if the person has trouble breathing or if their breathing doesn't return to normal.
- **Injury during seizure:** If the person sustained an injury during the seizure, such as a significant fall or bite, especially if it's a head injury.
- **No recovery post-seizure:** If the person does not start to wake up or return to their baseline level of consciousness after the seizure ends, or if they seem particularly ill or show signs of other significant complications.