

# Pack 113, Item 6

Type: Script

January 2020

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**Dementia: What it is and how to support a family member with dementia**

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**Notes to broadcaster**

Dementia is a general term that describes a wide range of symptoms associated with a decline in memory or other thinking skills that is severe enough to reduce a person’s ability to perform everyday activities. It is estimated that 47 million people live with dementia globally and 63% of these live in low and middle-income countries. The number of people with dementia is set to rise to 75 million by the year 2030 and 131.5 million in 2050, with much of the increase in developing countries.

Alzheimer’s disease accounts for 60-80% of dementia cases. But there are many other conditions that can cause dementia symptoms, including some that are reversible, such as thyroid problems and vitamin deficiencies.

Dementia is often incorrectly referred to as “senility” or “senile dementia.” This reflects the formerly widespread but incorrect belief that serious mental decline is a normal part of aging.

People with dementia may have problems with short-term memory, keeping track of a purse or wallet, paying bills, planning and preparing meals, remembering appointments, or travelling out of their neighbourhood.

Dementia is an overwhelming experience not only for the people who have it, but also for their caregivers and families. There is a lack of awareness and understanding of dementia in most countries, resulting in stigmatization and barriers to diagnosis and care, which impacts caregivers, families, and societies physically, psychologically, and economically.

This script illustrates the behaviour shown by people who have a dementia diagnosis, and addresses the care required from family and caregivers.

You could use this script as inspiration to produce a similar program on dementia and/or Alzheimer’s disease on your station. Or you might choose to present it as part of your regular health program, using voice actors to represent the speakers. If so, please make sure to tell your audience at the beginning of the program that the voices are those of actors, not the original people involved in the interviews.

If you create your own programs on dementia and Alzheimer’s disease, talk to people who with dementia or Alzheimer’s in your area, talk with their family and caregivers, and talk to medical experts. You might ask them:

Sig tune up then under

* How much do local people know about dementia and Alzheimer’s disease?
* How are people with dementia and Alzheimer’s disease treated in your area?
* What kind of supports for individuals and families, if any, are provided by government or civil society organizations?
* What are the most difficult aspects of caring for someone with dementia or Alzheimer’s? Have you found ways to address these challenges that might work for others?
* Do you think governments should support individuals and families who are dealing with dementia and Alzheimer’s? If so, how?

The estimated running time for this item, with signature tune, intro, and extro, is 20 minutes

**Host:** Did you know that an estimated 47 million people worldwide live with dementia and that a new case of dementia is diagnosed every three seconds?

In today’s program we are going to learn more about dementia: the difference between dementia and Alzheimer’s disease, causes of the condition, and the care needed for someone with dementia.

Signature tune up and out under

**Host:** Hello and welcome to *Your health* program. My name is Winnie Onyimbo. Dementia is overwhelming not only for the people who have it, but also for their caregivers and families. There is a lack of awareness and understanding of dementia in most countries, resulting in incorrect diagnosis, poor care, and stigmatization. In our program today, we speak to Elizabeth Mutunga, CEO and founder of Alzheimer’s and Dementia Organisation Kenya, or ADOK. She will tell us how a dementia diagnosis in her family changed her life. We shall also be hearing from Dr. Sokhi, a neurologist. Dr. Sokhi will tell us the cause of dementia, the common types of dementia, and how to take care of a person with the condition.

I first spoke with Elizabeth about her experience living with her dad who was diagnosed with dementia.

**eLIZABETH MUTUNGA:** My father started showing unusual behaviour. We knew there was a problem when he moved our family from a big mansion to a very small tin house and started selling his car in small bits. This shocked us, because my father was a senior policeman and an organized man. Unfortunately, we did not know what it was until 15 years later when we got the diagnosis that he had dementia. It was the first time I heard that word, and we were all confused because it was not a common diagnosis.

**Host:** Elizabeth Mutunga’s life changed drastically when her father started showing signs of dementia when she was just in high school. It was difficult to go through school because the main breadwinner was not able to provide. This meant that she had to get a job to take care of her siblings as well as support her mother, who was her father’s caregiver.

**ELIZABETH MUTUNGA:** After the diagnosis, we had no more information about the condition. Most of the people we talked to said it was a Western disease. It was only much later that we found a neurologist who was able to advise us on the care my dad needed. It took a toll on our family. My mum went into a depression, and at some point I was also depressed. But I had to step up because I was the firstborn and the rest had to go through school. We took care of him for 20 years.

**HOST:** Dr. Sokhi is a neurologist in Nairobi who deals with cases of dementia. He explains what dementia is.

**Dr. sokhi:** Dementia is a term that is used when one shows symptoms of having memory problems. A person with dementia has issues with a kind of brain functioning that is known as cognition. Cognition includes memory and other aspects of brain functioning, and may affect one’s ability to interact well in social situations and perform complex tasks. If a person has any of these two brain functions affected and cannot live life as independently as he or she used to, this would be termed dementia. There are many types of diseases that affect the brain which may lead to dementia and the most common type is Alzheimer’s disease.

**HOST:** Getting medical help for dementia in Kenya is very difficult as there are only 18 neurologists in a country of more than 45 million people. It is also still not clear how widespread dementia is in the region because there is very little information about it. I asked Dr. Sokhi why this is the case.

**DR. SOKHI:** Dementia is a nervous system condition, and diseases of the nervous system have not been given so much attention in Africa. Therefore, there is a lack of knowledge about them. Unfortunately, there is also a cultural aspect to it. In this part of the world, having a memory problem is taken as a normal part of aging and medical attention is rarely sought. That’s why you find little information about dementia in Africa.

**HOST:** Although dementia affects older people, it is not a normal part of ageing. The exact symptoms vary with the type of dementia, the stage of the disease, and from person to person. For Grace Njoroge, symptoms of dementia started when she lost her husband 10 years ago. Her daughter Angela is her caregiver.

**ANGELA** **Gaithumi:** My mum started showing signs right after my dad died. At first, we thought it was her way of coping with dad’s death, but the unusual behavior persisted.

 **HOST:** What did she do that made you think she was not well?

**ANGELA GAITHUMI:** She started acting out of character. For example, she would withdraw large amounts of money and forget that she did—and if asked, she would get violent. Mum was very educated and was working for the United Nations. That’s when we thought something was not right. Getting a diagnosis for her was not so difficult because we had been dealing with brain doctors because of my father’s case. One of the doctors suggested we see a neurologist for tests after we explained mum’s behaviour. That is when we got a diagnosis. But even after that, it was difficult because friends and the extended family did not quite understand. They always assume that dementia is a mental problem.

**HOST:** Dementia is a brain illness that affects memory. But how badly is memory affected? Dr. Sokhi explains.

**DR. SOKHI**: In dementia, short-term memory is affected first. People forget recent events. For example, they might struggle to remember what they had for breakfast, or where they left their keys, or they may forget appointments that were set even a day earlier. Later, as the illness progresses, people get confused about things like when they graduated, which school they went to, or if they are married or have children. Their conversation may become repetitive. As time goes on, the part of memory that is responsible for remembering names, categories, numbers, and calculations is also affected. So it starts with short-term memory and eventually affects all memory as time progresses.

**HOST:** Is there a cause—or something that may trigger dementia?

**DR SOKHI:** There is nothing that we know of. For Alzheimer’s, which is the commonest type of dementia, it is a disease that begins by itself. There are other types of dementia that may occur as a result of some conditions like HIV and AIDS, syphilis, or recurrent head trauma where the dementia is related to the injury.

**HOST:** Research shows that women bear a large amount of the burden of dementia. Aside from the fact that at **age 65, women have a higher chance of developing Alzheimer’s** and dementia compared to men, **most dementia caregivers are women**. Taking care of someone with dementia can be quite difficult for the family. They are stressed physically, emotionally, and economically.

In Elizabeth’s case, her dad could not recognize her as his daughter and refused to walk her down the aisle at her wedding. She was affected and even struggled with self-esteem for some time and had to undergo counselling. Because of the stress of being his caregiver, Angela’s mother would sometimes become violent.

**ANGELA GAITHUMI:** At times she would get frustrated and get very violent. Such times are very difficult because you cannot fight with your mother. Culturally in Africa, it is not right to see your mother’s nakedness. My sister and I had to cope with that so that we could take care of our mother.

**HOST:** The caregivers and family of the person with dementia need support from health, social, financial, and legal systems. In both Elizabeth and Angela’s cases, their loved ones with dementia would sometimes withdraw very large amount of money without notifying the family. Dr. Sokhi offers advice on what should be done when families see such behaviour.

**DR. SOKHI:** It is better to manage the behaviour at the home level. This is because there have been only four types of drugs that help control dementia for the past 15 or 20 years. Nothing new has come on the market that gives promise to stabilize or improve dementia symptoms. So 90% of the care is driven by the understanding of caregivers, friends, and family at home, or in the work situation. They are the ones who deal with the symptoms of dementia, and how to manage it.

**HOST:** Please give me some practical examples of how they would step in to manage the symptoms.

**DR. SOKHI:** For example, if the person can no longer manage their finances and they sometimes withdraw large amounts of money, the family should take steps to legally manage the finances of this person. If the person can longer work, engage with the employer and say “this is the level of work the person can or cannot do,” or suggest early retirement if the person cannot safely perform their duties.

**HOST:** Does a person with dementia get better with good care?

**DR. SOKHI** Dementia is a progressive disease. This means that the person does not get better. In fact, with time they may get worse and require healthcare assistance. For example, they will need help with feeding, washing, and dressing. If a person with dementia tends to wander away, or has problems navigating through the house or in the neighbourhood, he or she will need someone with them all the time to make sure they do not get lost.

**HOST:** One major challenge is the lack of government support for people with dementia and their families. There is no legislation, policies, or provision of services. It took Angela and her family 15 years to be able to manage her mother’s assets because she was not able to do it herself. Something as simple as getting legal access to her mother’s bank account took years and the process was very long.

**ANGELA GAITHUMI:** It is also very difficult to get good caregivers. Physical and sexual abuse can happen when the caregiver does not have a heart for people with dementia—even when they are well-trained caregivers. It took us a long time to find someone to come and assist us with mum, and we still need to have someone there full-time. I decided to quit my job because I needed mum to be taken care of well.

**HOST:** Inadequate information on the side of the caregivers, family, and society makes dementia even more complicated. That is why there is a lot of stigma. Many families have been accused of bewitching their ill family member. For the family and caregivers, not knowing how to deal with the person with dementia sometimes causes more problems. Like in the case of Elizabeth’s family.

**ELIZABETH MUTUNGA:** One time, we thought he needed a break and we took my dad out of town for some time. His behaviour worsened every time we moved him. We later realized that changing his surroundings was a bad idea. We learned simple things like not arguing with them even when they don’t make sense because it just aggravates them more.

**HOST:** Dr. Sokhi sheds some light on some of these behavioural changes.

**DR. SOKHI:** The behaviour changes are the most challenging for the family and caregivers. A person with dementia may feel very low and may not want to interact with anyone, or he may be very hyperactive and sometimes even aggressive. They may even lash out at their loved ones. The family and the caregivers need to understand that it is not the fault of the person with dementia. People with dementia can do well in familiar surroundings. They should not be taken to strange places for long periods of time because they get disoriented very quickly.

**HOST:** That was Dr. Sokhi, a neurologist in Nairobi, Kenya, explaining how to deal with a person with dementia.

 After living with someone with dementia and learning a lot about it from experience, Elizabeth Mutunga started the Alzheimer’s and Dementia Organisation Kenya (ADOK) in 2016. It is a caregivers-led organization where caregivers share their experience and challenges and learn from each other. Angela benefits from the support group and attributes most of what she has learnt and the support she gets from interacting with other caregivers. Dr. Sokhi also attends the meetings from time to time to share medical information and ways in which caregivers can better take care of their loved ones. Members of ADOK are currently advocating for dementia care to be included in key government health strategies. Because of this, there is a little more information about dementia in the country and the caregivers have a place where they can go to get emotional support.

Sig tune up then under

**HOST:** Thank you for staying with me for this program where we have learnt about dementia. We heard from Dr. Sokhi, a neurologist in Kenya, on what dementia is, its causes, and how to take care of a person with dementia. We also heard from Elizabeth Mutunga, the founder of Alzheimer’s Dementia Organisation of Kenya (ADOK), an organization she founded to support the caregivers of people with Alzheimer’s. Finally, we heard from Angela Gaithumi, who is the main caregiver to her mother, who was diagnosed with dementia 10 years ago. Until next week, this is your host for *Your health*, Winnie Onyimbo.

## Acknowledgements

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**Sources of information**

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# Why Is Alzheimer’s More Likely in Women? <https://www.alzheimers.net/8-12-15-why-is-alzheimers-more-likely-in-women/>

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