FRONTOTEMPORAL DISORDERS

THE MANY NAMES OF FTD

1.8 Contact Hours

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INSIDE THIS COURSE

Frontotemporal Dementia (FTD) is not a single brain disease. It is a family of neurodegenerative diseases. Collectively these are called frontotemporal lobar degeneration (FTLD). These diseases affect approximately 50-60,000 Americans.

Diseases Associated with FTD

- Behavior Variant (bvFTD)
- Temporal/Frontal Variant
- Pick's Disease
- Primary Progressive Aphasia (PPA)
- Progressive Non-fluent Aphasia
- Semantic Dementia
- Corticobasal Syndrome (CBS)
- Progressive Supranuclear Palsy (PSP)
- FTD with Parkinsonism
- FTD with Amyotrophic Lateral Sclerosis (FTD-ALS)
- Frontotemporal Lobar Degeneration
- Dementia with Lobar Atrophy and Neuronal Cytoplasmic Inclusions
- Diffuse Degenerative Cerebral Disease
- Lobar Atrophy of the Brain
- Wilhelmsen-Lynch Disease
- A subtype called Hippocampal Sparing AD (often misdiagnosed as FTD)

Course Description

This continuing education course is intended to increase the knowledge and skills of those who are called upon to care for people who have been diagnosed with a frontotemporal disorder. It includes relevant information for all medical professionals who come in contact with persons who have been diagnosed with a frontotemporal disorder and may have difficult behaviors, and lack awareness that they have a serious illness. These patients may be seen at home with a caregiver, in doctors' offices, in hospitals, mental health settings, long-term care communities, and other settings.

Course Objectives

- Identify the characteristics of frontotemporal disorders.
- List the common behavior symptoms.
- Describe several examples of treatment modalities.
- Recognize essential special care and safety needs.
- Identify available treatments and therapies.

INTRODUCTION

Frontotemporal disorders are currently widely underdiagnosed. FTD can be an inherited disease, but if no one in the family had it, perhaps the genetic mutation started with the person under your care. If so, his or her children have a 50% chance of getting it too. FTD is fatal, and most people die within five to 15 years after their first symptoms. There is no treatment, no cure, and currently no way to slow the ongoing course of the disease.

Frontotemporal Dementia (FTD) describes a clinical syndrome associated with shrinking of the frontal and temporal anterior lobes of the brain. Originally known as Pick's disease, the name and classification of FTD has been a topic of discussion for over a century. The presence of abnormalities in the nerve cells of the brain, called Pick bodies, distinguishes frontal lobe dementia from other types of dementia.

As it is defined today, the symptoms of FTD fall into two clinical patterns that involve either:

- Changes in behavior
- Problems with language

The first type features behavior that can be either impulsive (disinhibited) or bored and listless (apathetic). It also includes inappropriate social behavior; lack of social tact; lack of empathy; distractibility; loss of insight into the behaviors of oneself and others; an increased interest in sex; changes in food preferences; agitation or, conversely, blunted emotions; neglect of personal hygiene; repetitive or compulsive behavior, and decreased energy and motivation. Often, the patient with FTD now has no personality, no likes, no dislikes, and will never smile. They will no longer recognize their family members. The doctors may diagnose this person with major depression, schizophrenia, bipolar and use other psychiatric terms.

The second type primarily features symptoms of language disturbance, including difficulty making or understanding speech, often in conjunction with the behavioral type's symptoms. Spatial skills and memory remain intact.

A higher proportion of FTD cases seem to have a familial component than more common neurodegenerative diseases like Alzheimer's disease. There is a strong genetic component to the disease, and FTD often runs in families. A variety of mutations on several different genes have been linked to specific subtypes of frontotemporal dementia. However, more than half the people who develop frontotemporal dementia have no family history of dementia. The risk of developing frontotemporal dementia is higher if you have a family history of dementia. There are no other known risk factors.

More mutations and genetic variants are being identified all the time, so the list of genetic influences requires constant and consistent updating. Signs and symptoms typically manifest in late adulthood, usually between the ages of 45 and 64, equally affecting men and women. FTD accounts for about 20% of young onset dementia cases. Currently, there is no cure for FTD.

CAREGIVING CHALLENGES

Often the FTD patient will become incontinent. They do not shower, brush their teeth or change clothes without supervision and prompting. They may even eat anything and everything in sight to include paper, pens and plants. The daily ongoing challenges can be daunting for the caregivers. Creating a safe environment is going to be the utmost goal. The other challenge is finding a place for them to live. A secure residence is a must, but may be more difficult to find since these disorders affect younger persons and will require more homework to find the right community that is also affordable.

Behavioral Changes

The most common signs and symptoms of frontotemporal dementia involve extreme changes in behavior and personality and can include:

- Increasingly inappropriate actions
- Loss of empathy and other interpersonal skills
- Lack of judgment and inhibition
- Apathy
- Repetitive compulsive behavior
- Decline in personal hygiene
- Changes in eating habits, predominantly overeating
- Lack of awareness of thinking/insight or behavioral changes

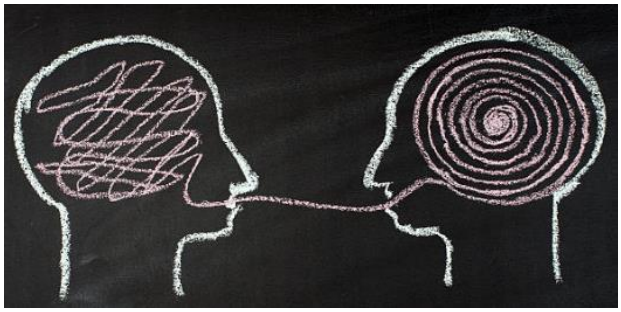
Patients with FTD may illustrate varying degrees of increased sexual desire. The bvFTD type is uniquely associated with hyper-sexuality; it is more than just cognitive impairment with frontal disinhibition but also involves alterations in sexual drive. A common issue is having extramarital affairs, or saying and doing inappropriate things in front of teenage children and their friends. This person may start shoplifting, and misbehave in other ways. They may laugh at a funeral and take food from another person's plate, especially cookies or bread products. These kinds of behaviors devastate families, especially when it is so out of character from that persons' previous personality.

Speech and Language Problems

Some subtypes of frontotemporal dementia are marked by the impairment or loss of speech and language difficulties.

Primary progressive aphasia, one subtype, is characterized by an increased difficulty in using and understanding written and spoken language. They often have trouble finding the right word to use in speech or naming objects. People with aphasia talk slowly and may have memory difficulties as well.

People with another subtype, semantic dementia, use grammatically correct speech that has no relevance to the conversation at hand. They may have difficulty understanding written or spoken language, or they may have difficulty recalling the words for common objects.



Movement Disorders

Damage to neurons in the frontal and temporal lobes of the brain cause the lobes to atrophy. This causes ongoing and progressive losses in thinking, behavior problems, emotional issues, trouble communicating and difficulty in walking, meal preparation, driving, working, and performing other daily activities. Rarer subtypes of frontotemporal dementia are characterized by problems with movement, similar to those associated with Parkinson's disease or amyotrophic lateral sclerosis (ALS).

Movement-Related Signs and Symptoms

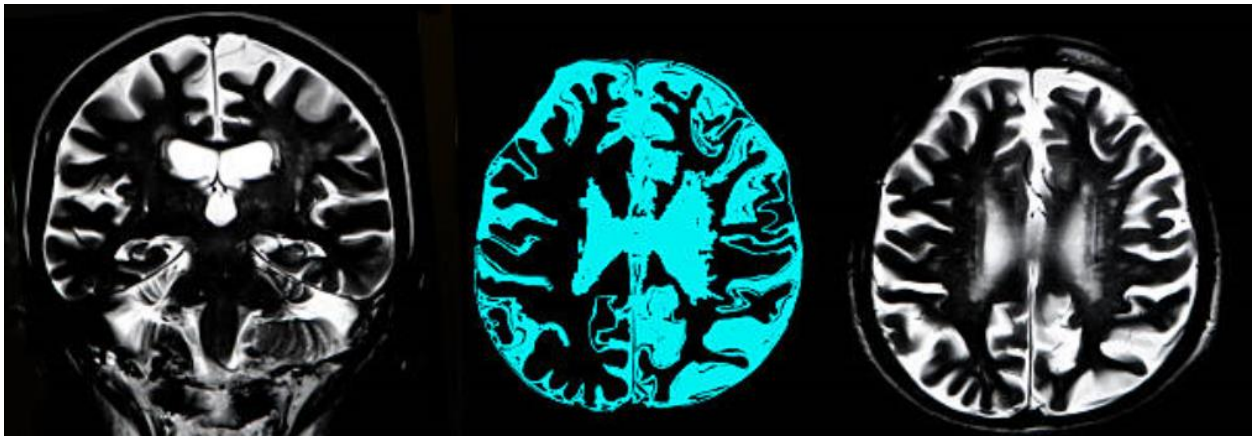
- Tremor
- Rigidity
- Muscle spasms
- Poor coordination
- Difficulty swallowing
- Muscle weakness
- Dystonia (abnormal and stiff postures of hands and feet)
- Shuffling and frequent falls

DEFINITIVELY DIAGNOSING FTD

An FTD diagnosis can be confirmed in two ways:

- Genetic testing in familial cases
- Brain autopsy after death

Gathering as much information from family members and looking over the medical history will start the probable FTD diagnosis process. The medical team would also want to order blood tests to uncover any possible genetic mutations and similar conditions. Neuropsychological evaluation will assess behavior, language, memory and other cognitive losses. Brain imaging testing will identify changes in the brain and shrinkage in the frontal and temporal lobes. An MRI may look normal on a person with FTD, so it would be best to use *positron emission tomography* (PET) or *single photon emission computed tomography* (SPECT) scans. These scans measure the activity in the brain by monitoring blood flow, glucose and oxygen usage. They can also rule out Alzheimer's or exclude other causes of dementia such as strokes and brain tumors, or could identify that this person has two or more co-existing dementias.



WHY IS GETTING A DIAGNOSIS SO IMPORTANT?

FTD is frequently misdiagnosed as Alzheimer's or a psychiatric disorder, its symptoms often overlap and look like these. FTD dementia poses a diagnostic challenge and its victims are quickly losing cognitive ground. They are not getting the correct treatment and understanding of their behaviors. They also lose valuable pre-planning time so they may make personal decisions based on what kinds of treatment and wishes they would like rather than having another family member or a guardian take over this aspect of their future medical and financial care needs.

Some patients with FTD develop Lou Gehrig's disease, also known as amyotrophic lateral sclerosis (ALS). Doctors don't yet fully understand the connection between the two diseases but are studying the trend.

Some of the important steps to getting a proper diagnosis include the following:

1. **Routine blood work**: Tests for specific chemicals, proteins, hormones and antibodies to detect conditions that can have similar clinical features to FTD, such as thyroid disease, B12 deficiency, infections such as syphilis or HIV, dehydration, or cancer. These conditions are treated differently, and some are manageable or curable.

2. **Neurological exam**: A detailed examination of the entire nervous system including physical and cognitive functioning. An initial evaluation usually takes about an hour and includes:

    - Obtaining a detailed past medical history.
    - Physical examination – evaluating motor function such as walking, balance, coordination, reflexes, strength, as well as vision, hearing and heart function.
    - Cognitive examination – evaluating memory, thinking, planning and organizational skills, visual-spatial abilities, behavior and mood.

Even among neurologists there are different specialties; therefore, it is not uncommon for an individual to see more than one neurologist. It is extremely important for an individual to be evaluated by a neurologist experienced with FTD and related neurodegenerative conditions. Neuropsychological testing can include:

- Pencil-and-paper tests and interviews that evaluate cognition and try to identify specific areas of strength and weakness.
- Measures of memory, concentration, visual-spatial, problem solving, and basic math and language skills. These tests take several hours to administer and are interpreted by a neuropsychologist.
- Differentiating depression from dementia, and can help in the diagnosis of specific types of dementia or brain disorders. For example, someone with Alzheimer's disease will show significant deficits in tests of memory while someone with FTD can do fairly well with memory but have more difficulty on language skills.

Note: There is a subtype (variant) of Alzheimer's disease (AD) that is called hippocampal-sparing AD. Because these younger (mostly male) patients have near normal memories, clinicians often mis-diagnose them with FTD. New evidence from the Mayo Clinic brain bank program suggests that this variant made up 11% of the AD confirmed brain autopsies. This research will help doctors to better understand that loss of memory is not present in every AD patient.

Where Pick's Disease Gets Its Name

First described in 1892 by Arnold Pick, a term now reserved for one specific type of frontotemporal dementia is Pick's disease. Unlike patients who suffer from Alzheimer's disease, patients with Pick's disease do not lose short-term memory. Pick was a professor of psychiatry in Prague, and was described as an intelligent, modest, and principled man who made substantial contributions to the fields of psychiatry and neurology through numerous publications. Pick's studies often included brain autopsy's to study size and/or shrinkage of specific brain regions.

FTD Symptoms

The person with a FTD disorder cannot control their behavior and lacks the understanding that they even have a problem. Impaired awareness of illness (anosognosia) is a major problem and it is important for the caregiver to not show anger and think this person is doing this on purpose.

Executive Functioning Problems – Cannot organize thought to figure out planning what steps come first, second, or third for an activity and then to shift to another task.

Perseveration – Repeating the same steps, word or gesture long after it makes no sense.

Social Disinhibition – Acting inappropriately at a social gathering, show an outburst of laughter at a tragedy, and not consider how others would perceive this strange behavior.

Compulsive Eating – Taking food from anywhere – off a grocery shelf, off another person's plate – or eating items that are not meant for human consumption like glitter, wallpaper, and plants. (There is another disorder called Pica in which a person may crave and ingest non-food items such as paint, plaster, string, hair, laundry starch, plastic, pencil erasers, freezer frost, fingernails, paper, coal, chalk, wood, plaster, light bulbs, needles, wire, cigarette butts, sand, or cloth.)

Utilization Behavior – Unable to resist grasping or using an object placed in front of them, regardless of the context or environment. For example, this person may see and use another persons' toothbrush. This demonstrates the appropriate action (brushing) but with the inappropriate usage. This dysfunction of the frontal area causes the inappropriate motor responses to specific objects in their visual field in the environment.

Finding Long-Term Care

The search for the right community begins with sorting out the options. There are several types of facilities that may be appropriate for someone with FTD. There are not yet facilities designed specifically for people with FTD, so it means finding the best match among the available options. Placement will depend on finding a balance between the level of support the patient requires and the skilled care needed to ensure safety and quality of life. Factors such as location and cost (Medicaid?) often determine the specific options available. Part of the placement problem may be the person's age. A lot of communities will not take residents under age 60.

Assisted living facilities (ALF) (*also called board and care, adult living, supported care*) bridge the gap between living independently and living in a nursing home. Assisted living typically offers a combination of housing and meals, and supportive and health care services. Definitions of assisted

living vary from state to state. ALFs are usually designed for people who do not have severe medical problems but who need help with personal care such as bathing, dressing and grooming, meal preparation and medication management.

Alzheimer's or dementia special care units are designed to meet the specific needs of individuals with Alzheimer's disease and other dementias. Special care units can take many forms and exist within various types of facility care. Such units most often are cluster settings in which persons with dementia are grouped together on a floor or a unit within a larger care facility. There are facilities, however, that are wholly dedicated to the care of people with dementia. Many families may find the closest fit for care of someone with FTD is in a dedicated dementia-care unit or facility.

Nursing homes (*also called skilled nursing facility, long-term care facility, custodial care*) are facilities with 24-hour medical care available, including short-term rehabilitation (physical therapy; occupational therapies and other services) as well as long-term care for people with chronic ailments or disabilities that require daily attention of RN's in addition to help with personal care such as bathing or dressing or mobility. Most nursing homes have services and staff to address issues such as nutrition, skin care management, care planning, recreation, spirituality and medical care. Nursing homes are usually licensed by the state and regulated by the federal government.

Psychiatric facilities serve patients with seriously agitated or aggressive behavior. Psychiatrists and nurses assist in the evaluation of medication interventions, and a secure environment helps to ensure patient safety. There are different types of behavioral mental health facilities from acute care community in-patient units to long-term state institutions.

Across all levels of care, the placement is more likely to succeed when family members develop a partnership with the facility administration and caregivers to work together in providing quality patient care. Frontotemporal degeneration is still unfamiliar to many facility providers. It will take a village of families, professionals, and supportive care team members to educate, advocate, and show support staff how to be an important member of the care team. Everyone involved will need to share the goal of providing the best possible care.

THE TRANSITION FROM HOME TO FACILITY CARE

People with frontotemporal degeneration often have difficulty adjusting to a new environment. The change means that for a time they may have difficulty finding things; feeling comfortable with new people and routines; they may feel frustrated or angry.

FTD families face an additional challenge in that most professional caregivers are not familiar with the behaviors common to frontotemporal degeneration, which are so different from those of Alzheimer's. FTD patients are typically younger and stronger so a different approach is needed to address aggressive behaviors that may seem to present a more physical threat to facility staff and residents.

The knowledge that family caregivers have is tremendously valuable to facility staff. Nurses and professional caregivers will not have as much experience as this resident's family, and are generally eager to learn what they can to provide good care. When family members appreciate the value of their own experience as well as the multiple demands on staff (from administrative changes, staff shortages or demanding residents), a trusting partnership can develop that benefits everyone, especially the patient. Even though the family has shifted the responsibility of day-to-day care over to the facility, it is important that they remain an active partner with the staff to ensure the right approach and best care for a loved one.

WHAT'S GOING ON?

When a person with FTD "acts out" the first step for professional caregivers is to observe and evaluate for physical ailments that may be triggering the behavior. Could they have a urinary tract infection? Are they arthritic and in pain? When was the last time their teeth/mouth was checked for sores, infected teeth or other oral concerns? Is there a fecal impaction, decubitus (pressure) ulcers, an upper respiratory infection like pneumonia? Have there been any changes in environment, roommate or medications lately? All of these could provoke anger and loss of control for the person with FTD. Sometimes we have to read what the problem is through their body language. Anti-depressants and tranquilizers have been shown to improve some symptoms.

AVAILABLE TREATMENTS

Since FTD is a multi-system disease the management of the disease will require a comprehensive treatment approach. This means that physicians and professionals from different specialties (e.g. neurologist, primary care, pharmacist, physical/occupational therapy, social worker, etc.) work as a team to collaborate to provide optimum treatment of each symptom without worsening other FTD symptoms. This can be accomplished in the home, through a home health agency, through an adult day program; in a rehabilitation center or in a long-term care environment.

MEDICATIONS AND PROPER USAGE

Antidepressants called selective serotonin reuptake inhibitors (SSRIs) may offer some relief from apathy and depression and help reduce food cravings, loss of impulse control and compulsive activity.

Doctors may prescribe anti-psychotics, medications that can alleviate extremely unrealistic or disorganized thinking such as hallucinations, delusions and aggression. Older anti-psychotic medications that block dopamine may be dangerous for FTD patients because some of them have Parkinson's disease, which causes a loss of dopamine, a chemical messenger that transmits signals within the brain.

Cholinesterase inhibitors - the class of drugs currently used to treat memory symptoms in Alzheimer's - do not help FTD patients. These drugs temporarily increase supplies of the messenger chemical acetylcholine to failing nerves, but FTD does not affect nerves in the acetylcholine communication system.

According to the NIH, the use of Alzheimer's medications to improve behavioral and cognitive symptoms in people with bvFTD and related disorders is being studied, though results so far have been mixed, with some medications making symptoms worse.

CERTIFIED GENETIC COUNSELOR (CGC)

CGCs provide information and support to individuals and families when there is a multi-generational history of dementia or an increased risk of an inheritable form of FTD. A CGC can review a family's medical history and analyze inheritance patterns, offer advice on potential inheritable risk factors, and offer guidance on options for more information including the possibility of genetic testing. CGCs are often part of the teams at specialized clinical or research programs at hospitals or medical centers. Some counselors have private practices or will work as a consultant to doctors or hospitals. You can find a listing of certified genetic counselors through the website of the National Society of Genetic Counselors (www.nsgc.org).

Therapeutic Ideas for Better Quality of Life

- **Physical therapy** can help with movement problems through cardiovascular, strengthening, and flexibility exercises, as well as gait training and general physical fitness programs.
- **Speech therapy** may help with low voice volume, voice projection, poor speaking ability, and swallowing issues.
- **Occupational therapy** can help identify problems with everyday activities, such as eating and bathing, and assist with and promote independence.
- **Music and art therapy** may provide meaningful activities that can reduce anxiety and improve well-being.
- **Mental health counselors** can help persons with FTD, their families, and caregivers to learn how to manage difficult emotions and behaviors and plan for the future.

SUMMARY

Currently, there are no cures for the common dementias caused by progressive neurodegeneration, including Alzheimer's disease, frontotemporal disorders, and Lewy body dementia. FTD, in its many forms, presents itself differently for each affected individual. This course is just a starting point for information and describes just a few of the endless possibilities of the disease variables. Understand that a person with FTD has a form of dementia and is not in control of their behaviors and cannot change. We must respond with appropriate interventions, empathy, and guidance for the patient and their family. By understanding dementia disorders, as well as their diagnosis and treatment, you can help affected individuals and their caregivers (professional and family) meet daily challenges and live their lives more fully.

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CE EXAM

FRONTOTEMPORAL DISORDERS

1. Which of the following is NOT a form of frontotemporal dementia (FTD)?

   A. Pick's Disease
   B. Alzheimer's Disease
   C. Progressive Supranuclear Palsy (PSP)
   D. Wilhelmsen-Lynch Disease

2. Over time, people with a certain form of FTD may develop symptoms similar to:

   A. Muscular Dystrophy
   B. Hippocampal Sparing AD
   C. Amyotrophic Lateral Sclerosis (ALS)
   D. Down's Syndrome

3. Various symptoms of FTD may include _____.

   A. Compulsive eating
   B. Lack of judgement and inhibition
   C. A decline of personal hygiene
   D. All of the above

4. _____ put(s) persons at the highest risk for developing FTD.

   A. Family history and genetics
   B. Old head injuries
   C. Mental illness
   D. Old age

5. FTD patients may exhibit language difficulties and movement disorders, as well as eating inappropriate items.

   A. True
   B. False

6. An MRI is the most accurate scan for identifying potential FTD patients.

   A. True
   B. False

7. Antidepressants called selective serotonin reuptake inhibitors (SSRI) often cause food cravings and impulsive activity in FTD patients.

   A. True
   B. False

8. Only a _____ can provide 100% confirmation that a person had FTD.

   A. Doctor’s evaluation
   B. Neurologist's confirmation
   C. Brain autopsy
   D. Toxicology test

9. FTD may create an indifference to others’ feelings by blunting emotions.

   A. True
   B. False

10. Typical behavior of a person with a form of FTD may include:

    A. Grabbing food off another’s plate
    B. Shoplifting
    C. Indifference to others' feelings
    D. All of the above

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EVALUATION

FRONTOTEMPORAL DISORDERS

Please answer the following questions by circling the response that best represents your experience.		Strongly Agree	Agree	Neutral	Disagree	Strongly Disagree
COURSE OBJECTIVES & CONTENT						
1.	The activity met the stated learning objectives.	5	4	3	2	1
2.	The content was up to date.	5	4	3	2	1
TEACHING/LEARNING METHODS						
3.	The teaching/learning methods, strategies, and slides were effective in helping me learn.	5	4	3	2	1
4.	The material was clearly explained.	5	4	3	2	1
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6.	The online course/download supported the achievement of the stated learning objectives.	5	4	3	2	1
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8.	Overall, I am pleased with this activity and would recommend it to others.	Yes	No			
9.	The content was presented free of commercial bias.*	Yes	No			
10.	Did the material presented increase your knowledge and/or understanding of this topic?**	Yes	No	NA		

Continued on Next Page

***** If you responded “No” to question 9, please explain why:

***** If you answered “Yes” to question 10, what change do you intend to make?

What barrier, if any, may prevent you from implementing what you learned?

Cite one new piece of information you learned from this activity:

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Understanding Implicit Bias

The goal of healthcare is to provide the best possible care to all patients; indeed, many healthcare professionals must recite a pledge similar to the Hippocratic oath upon licensure. However, it is possible for healthcare professionals to have implicit bias that leads to substandard care.

Implicit bias is an unconscious attitude leading to stereotypes that influence thought and action. Not being aware of this bias can lead to unintentional discrimination in patient assessment and diagnosis, treatment, follow-up care, etc. Discrimination, unconscious or otherwise, in these impacted areas of healthcare leads to disparities where disadvantaged patient populations receive unequal care. Patient groups especially at risk of receiving unequal care may include:

- Those with lower income
- Women
- Minorities
- Those who speak English as a second language
- The elderly

An example of healthcare disparities can be seen in breast cancer mortality rates. Black women are 41% more likely to die from breast cancer than white women. Additionally, they are less likely to be diagnosed with stage I breast cancer, but twice as like to die from early breast cancer.

Eliminating implicit bias can help reducing disparities in healthcare. Strategies for healthcare professionals to remove bias from their practice may include:

- Regulating emotions – being aware of, and control, thoughts and feelings
- Building partnerships – working with patients to achieve a common goal
- Taking perspective – understand the patient perspective during all phases of healthcare

Recognizing implicit bias and working to remove it from practice will help healthcare professionals to give the best care possible to all patients and reduce the disparities between patient populations.

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