NATIONAL MINORITY QUALITY FORUM

LIFTEVERYVOICE PATIENT NETWORK

Before Diagnosis Navigation Toolkit

Stronger Minds, Stronger Families

Alzheimer's Awareness & Action

Let's Talk about Alzheimer's

According to the Alzheimer's Association, Alzheimer's is a brain disease that affects nearly 7 million Americans nationwide.[1] It's the most common type of dementia that destroys the memories and thinking process of a person and makes it difficult for people to perform tasks that used to be second-nature to them. The brain's going through too many changes, that even their personality and behaviors can change, making them seem like a different person. And as time goes on, the damage to the brain gets worse.

Why is Alzheimer's so Complicated?

Alzheimer's looks different on everyone and the early changes can be too small to notice. For the person going through it, it's terrifying to notice the changes so some try to hide it from others, hoping they're overthinking their memory challenges. Others think it's normal signs of aging and ignore it until it gets too bad.

Alzheimer's is Harder on People of Color

Did you know?

~21% of Black people over the age of **70** & **~13%** of Hispanic people in the U.S. over the age of **65 have Alzheimer's?**[1]

Even with what we know, people of color still face delays in getting diagnosed and starting treatment. Their concerns about memory issues are often dismissed or misinterpreted, which means they usually get diagnosed and treated later.

Symptoms vary between individuals, and they also differ among racial and ethnic groups. **Black and Hispanic people often experience more agitation, irritability, depression, and anxiety.**[2] Their symptoms are usually more severe and get worse faster, often because they receive treatment later.[3]

Additionally, people of color with Alzheimer's may show signs like delusions, hallucinations, abnormal sleep, agitation, and language problems earlier than white people typically do.

What Causes Alzheimer's?

The disease happens when abnormal proteins build up in the brain, forming plaques and tangles that harm nerve cells.

We're still figuring out why these proteins build up, but there are several factors that can increase the risk:

Genetics

There are different genes that are involved with Alzheimer's, and some are more common in Black people and Hispanics than in other races.

Other health conditions

Conditions like high blood pressure, diabetes, and cardiovascular disease are risk factors for Alzheimer's, which are higher in Black and Hispanic communities.

Environment

People of color have historically lived in underfunded communities, often living near industrial facilities, that increase the risk of environmental and hazardous exposures that negatively affect their health. These underfunded areas also have less access to healthy foods, less recreational parks and outdoor safety, and poorly funded schools that have long term effects on their health. This is especially true for Black and Hispanic communities.

Stress

People of color have higher rates of chronic stress than white people, including discrimination, limited access to resources, socioeconomic status, and barriers that prevent growth. People of color are more likely to become caregivers to their family members, which contributes to the stress of balancing work and family needs.

Unequal access to healthcare

Communities of color tend to have less access to healthcare resources, either they're too far away or they're too expensive. When they do have access to healthcare, they often tend to have less quality of care which results in late diagnoses and treatment for many chronic illnesses, which can contribute to higher risk of developing Alzheimer's when they're older.

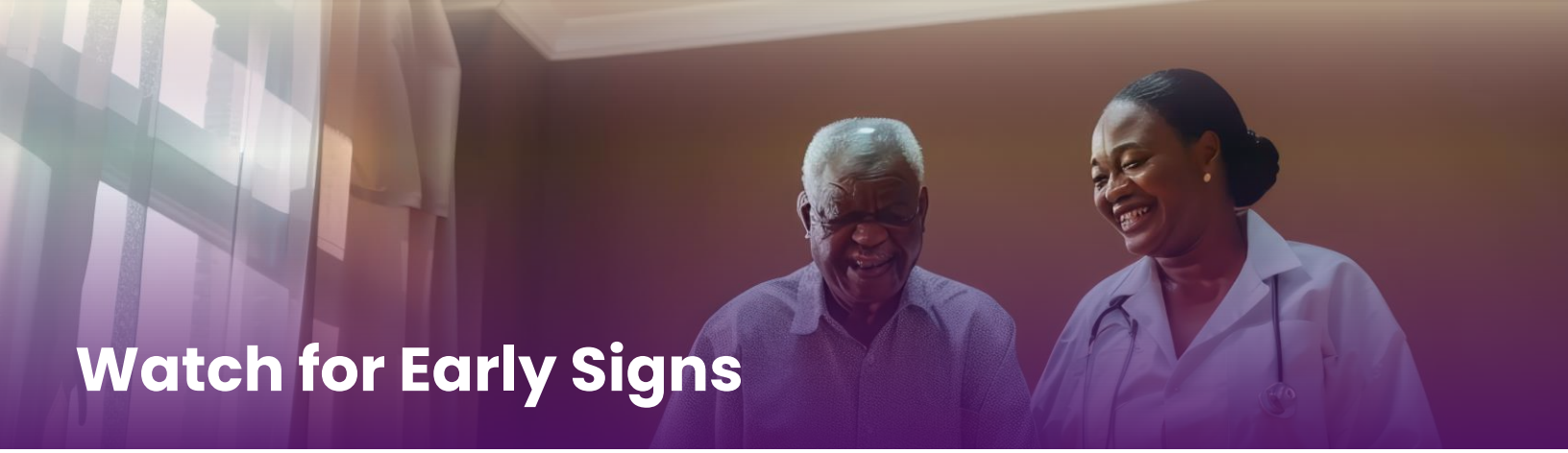
What's the Latest on Alzheimer's Research?

Researchers are still trying to understand Alzheimer's disease. Right now, not enough people of color are joining research studies, which means we learn less about how the disease affects these communities. Studies suggest that Black and Hispanic people are much less likely to have heard about clinical trials compared to white people.[4] In addition, because of past mistreatment and ongoing unfair care, many people of color don't feel safe participating in research. However, efforts are being made to create a safer environment so we can learn more about Alzheimer's among all groups.

Some studies have found that even people without memory problems can have Alzheimer's plaques—clumps of harmful proteins—in their brains.[5] Over time, these plaques can lead to memory loss and other symptoms. This shows that the plaques start to build up long before any symptoms appear. Researchers hope to find ways to stop or slow this build-up so the disease might be prevented.

As more people of color take part in research, we are discovering that Alzheimer's can look different in different communities. For example, brain scans might show different patterns in people of color compared to white people, which can sometimes lead to misdiagnosis and delays in treatment. Different genetic factors in various communities also play a role in Alzheimer's risk. Researchers are beginning to understand which genes are involved, but there's still a lot to learn.

In short, increasing diversity in research is essential for developing better treatments that work for everyone.



Watch for Early Signs

It's a quiet and scary struggle when you start noticing changes in yourself or a loved one – small moments when your memory isn't as sharp, forgetting the names of loved ones, often losing track of time, or having trouble with tasks that used to be easy.

It's easy to keep these concerns to yourself, brushing it off as stress or normal side effects of aging. However, these changes are important to keep an eye on and share with the people you love and your doctor. It may just be nothing, or it may be something as serious as Alzheimer's disease.

For people of color, it can be harder to get the right answers or be heard when it comes to something like Alzheimer's, especially in the early stages.

Understanding Alzheimer's Disease

Alzheimer's disease is the most common type of dementia, and it's more than just forgetting things.[6] It's a brain disease that attacks the brain, making it harder to think clearly, remember things, and make decisions. It can change a person's behavior, their relationships and their everyday life. This is a disease that gets worse over time, especially if it isn't treated. There is no cure for Alzheimer's, but it is important to start treatment as soon as possible to slow the disease down.

Many people think forgetting things is just a normal part of getting older. But that's not true. Healthy older adults have healthy brains and memory.

Memory Loss or Something More?

Recognizing Alzheimer's in Our Communities

Understanding Alzheimer's and How it Affects People of Color

Alzheimer's disease can sometimes be tricky, especially in the early stages. For people of color, the signs can be harder to spot because they may show up differently than they do for other groups. Early diagnosis is key when it comes to Alzheimer's, but people of color face many challenges when trying to get the care that they need. That's why it's important to know the warning signs and take action when something doesn't feel right.

Common Alzheimer's Symptoms

Alzheimer's doesn't look the same for everyone, but here are some of the most common signs to keep an eye on:

Memory Loss

Forgetting something once is normal, but forgetting important dates, names, or conversations often is not something to ignore.

Difficulty with Daily Tasks

Forgetting how to do things you've done several times, like paying bills or following a recipe.

Confusion with Time and Place

Constantly losing track of time or getting lost in familiar places.

Trouble with Words

Struggling to find the right words when talking or repeating yourself more than usual.

Mood and Personality Changes

Feeling confused, anxious, easily upset, or noticing that your personality is changing.

Poor Judgement

Making bad choices, such as giving away a lot of money or making unsafe decisions.

Hallucinations and Delusions

Seeing or hearing things that are not there, or believing in delusions such as people looking for them.

Symptoms That Often Get Missed

Sometimes the symptoms of Alzheimer's are small and subtle and they look like something else, so they can be easily missed. Some symptoms that people tend to ignore are forgetfulness; trouble focusing; agitation or confusion at night; changes in sleep patterns, misplacing items; and trouble with speaking.

When Do Alzheimer's Symptoms Appear

Alzheimer's usually shows up in someone's mid-60's or later. However, it rarely can also start before the age of 65, sometimes even in someone's 30's. This is called early-onset Alzheimer's.[1]

Alzheimer's symptoms start slow, which is why it can be so hard to notice at first. But overtime, the symptoms of Alzheimer's get worse. You may first notice small memory lapses or difficulty completing everyday tasks. It's so important to pay attention to these changes early on because it takes much longer for people of color to receive a proper diagnosis.

How to Track Your Symptoms

Alzheimer's can get worse faster in Black and Hispanic people for several reasons. Stress and discrimination can lead to other health issues like high blood pressure and diabetes, which can make Alzheimer's symptoms worse. It's important to watch for changes in your memory, thinking, or mood so you can get help early.

If you or someone you love notices these signs, it's a good idea to:

Keep a journal

Write down any changes and how often they happen, what seems to trigger them, and how long it lasts.

Look for patterns

Do their symptoms get worse when they're stressed, tired, or after the sun sets? Pay attention to those patterns.

Here's What You Can Do

If you or a loved one are showing any signs listed above, the most important thing that you can do is to see a doctor and ask for tests to be done for Alzheimer's.

While you wait for this appointment, here are some things you can do to:

Talk About It

Talk with your family and friends about Alzheimer's. When you share your concerns, you can get better care and support from doctors and your community.

Brain Stimulation

Do activities that challenge your brain, like puzzles, reading, listening to music, playing games, cooking, gardening, or spending time with others. These activities help keep your brain strong, especially when combined with treatment.

Exercise Regularly

Exercise helps your brain by improving memory, concentration, sleep, and mood. Regular physical activity may even slow the progress of Alzheimer's.

Reduce Stress

People of color, especially Black and Hispanic communities, often face higher stress levels, which can worsen Alzheimer's. Work with your loved ones to find ways to relax. Look for local support groups that teach stress relief and mindfulness.

Eat for a Healthy Brain

Choose foods that are good for your brain, such as leafy greens, berries, fish, whole grains, beans, and nuts, and drink plenty of water. These foods give your brain energy and may help reduce harmful inflammation and slow down damaging protein build-up.

Alzheimer's can be frightening, but by talking about it and taking steps to care for your brain, you can help protect yourself and your community. Standing up for better care and treatment benefits everyone.

When to See a Doctor

If you can relate to this guide, then it's time to call your doctor. If you've noticed memory issues or other changes that are affecting your daily life, you need to talk to your doctor as soon as you can. You don't have to wait for things to get harder or confusing. You take control of it now.

The sooner you talk to your doctor, the better it is for you and your brain. Early diagnosis can help manage your symptoms and slow down Alzheimer's. It gives you more time to live your life the way you want, to plan for your future, get the support you need, and live as independently as possible for longer.

Doctors Who Can Help

Once you start to notice symptoms, it's important to see the right professionals. Here are some doctors that you may see:

Primary Care Physician

Your primary doctor can perform the initial evaluation, check for other conditions, and refer you to see a specialist.

Neurologist

This is a brain specialist. They diagnose you and talk over treatment options with you.

Geriatrician

This kind of doctor specializes in health care for older adults. They provide comprehensive care, so they can help if you've been diagnosed with Alzheimer's and other health issues.

Psychologist/Psychiatrist

If you're experiencing mood swings or anxiety, these professionals can offer ways to help manage these feelings.

How to Talk to Your Doctor

If you or a loved one start to notice these symptoms, it's important to see a doctor.
Starting treatment early in the stages of Alzheimer's will help control the disease and improve quality of life. Don't be afraid to ask your doctor about any changes you have noticed. If you feel like your concerns are being dismissed, don't be afraid to get a second opinion. Medical discrimination, unfortunately, is real.

But don't let that stop you from getting the care you need!

It can sometimes be scary going to the doctors to talk about complicated illnesses, but it doesn't have to be so overwhelming. Here are a few tips to help you have a better appointment:

Before your appointment

Track changes

Write down any changes you or your loved ones have noticed in memory, mood, or behavior.

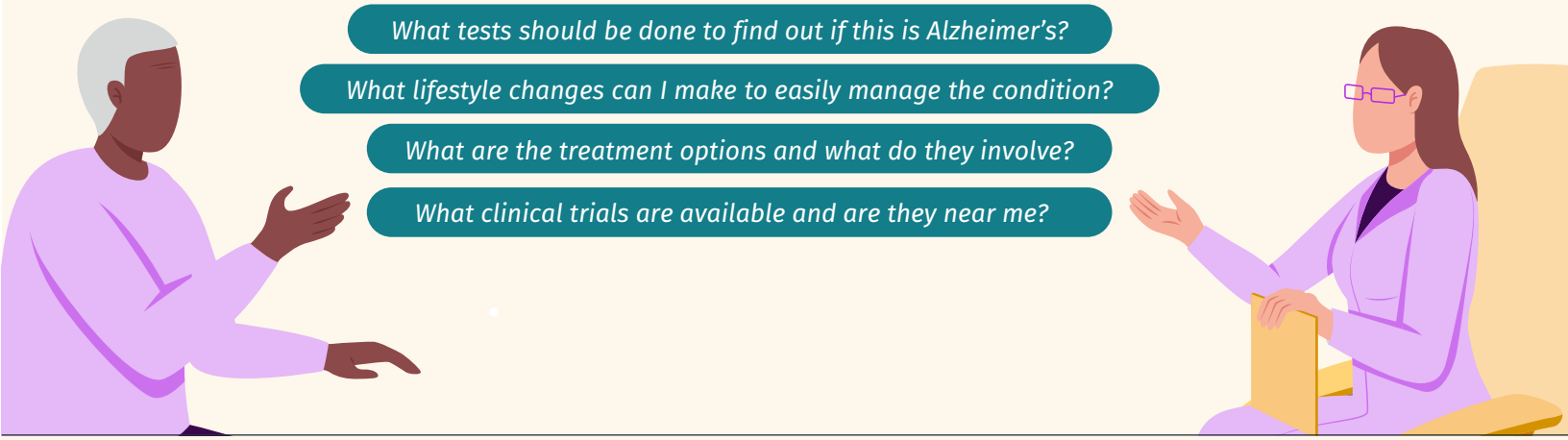
List questions

Take some time to write down any questions or concerns you and your loved ones have. This will help make sure you don't forget anything during the appointment.

Do your research

Doctors will say a lot of information in a short time. Research different testing options, **like CT scan, MRI, PET scan,** so you know what to expect when you get tested.

Some questions to ask can be:



During your appointment

Bring support

The stress and anxiety of doctor's visits already make us have a hard time understanding and remembering everything the doctors tell us. Bring a loved one, someone you trust, with you to the appointment for support. They can help you remember important things and take notes for you.

Advocate for yourself

If the doctor starts talking in big medical terms, ask them to simplify it to you to make you better understand what is happening and what is going to be done to help. If the doctor dismisses you, request for testing. Brain scans, mental ability tests, blood tests, ask for them all! If they deny, tell them to write in your medical notes that you requested these tests to be done, but they denied it. They might give you the tests then.

Take Action Early

Alzheimer's is a challenging disease, but the earlier you catch the symptoms and talk to your doctor, the better you can manage it. By recognizing the early signs of Alzheimer's and seeking help, you're taking control of your health. Our voices matter, and we deserve to be heard and treated with respect. Be proactive about your health and take action early for a better future.

Alzheimer's Stigma Stops Here

Awareness, Action & Advocacy

Let's Talk About Stigma

Talking about Alzheimer's can feel really hard, but it's important to do so. Starting the conversation might feel scary or awkward because of strong feelings and old, negative ideas about the disease. This fear, or stigma, stops many people from talking openly with family and doctors, which means they might not get the help they need.

Many people keep Alzheimer's a secret because they worry others will see them as weak. This silence can hurt families, especially when they deny the problem or avoid seeking help because they fear being judged. For Black, Hispanic, and other marginalized communities, these negative views hit even harder.

Breaking the silence and talking about Alzheimer's can help reduce fear and lead to better support, including medical care.

Stigma's Stronghold: How it Negatively Affects People with Alzheimer's

Stigma, or the negative ideas about Alzheimer's, stops many people from getting the care they need. This stigma can lead to late or wrong diagnoses and poor access to treatment. It also makes many people think that memory loss is just a normal part of getting older, which isn't true. These false beliefs stop people from seeking help or even recognizing their symptoms.

In many marginalized communities, cultural and historical factors make this stigma even worse for elders. For people of color, Alzheimer's is sometimes seen as a source of shame or a sign of weakness. In cultures where elders are respected for their wisdom and strength, losing mental abilities can feel like a loss of dignity and value. This makes it even harder for elders of color to talk about what they're experiencing.

This stigma can lead to late or wrong diagnoses and poor access to treatment.

Cultural Attitudes Towards Alzheimer's

Alzheimer's is often avoided in conversations, especially in Black and Hispanic communities, where memory loss is seen as a normal part of aging. Changes in behavior are sometimes dismissed as "crabby elders" rather than signs of Alzheimer's, and many are afraid of seeking help due to shame or fear of weakness. In these cultures, elders are highly respected, and Alzheimer's can be seen as a threat to their dignity and wisdom. Admitting to memory problems is often avoided to protect this image, leading to denial and reluctance to seek medical care.

For these families, there's a strong pressure to maintain a perfect family image, which can discourage discussing health issues and seeking help. Many families also believe "what happens in this family, stays in this family," preventing them from seeking community support. This leads to caregivers feeling isolated and overwhelmed, further adding to the stigma and stress.

Stigma Worsens the Health of People of Color

Negative ideas about Alzheimer's stop many Black and Hispanic people from getting care.

Because there isn't enough understanding or care that fits their culture, these groups often get diagnosed too late, when the disease is more advanced. This delay makes treatment less effective and harms their health even more.

A Path Forward: Raising Awareness to Combat Stigma

Combating Alzheimer's stigma requires awareness through education and community support. The first step is to start talking, with your family, friends and community members. Here are some simple ways to fight the negative ideas about Alzheimer's:

Talk Openly

Start conversations with family, friends, and neighbors to clear up misunderstandings about Alzheimer's.

Challenge Stereotypes

Speak up when you hear wrong ideas about memory loss or aging.

Promote Positive Stories

Share real experiences and success stories about living with Alzheimer's.

Educate Yourself and Others

Learn the facts about Alzheimer's and share what you learn to break down myths.

Advocate for Better Care

Work with local leaders to push for healthcare that understands and respects different cultures.

Support Those Affected

Encourage and help people with Alzheimer's get the care they need.

Build Community Groups

Join or create groups where people can safely talk about Alzheimer's without judgment.

These steps can help change minds and make it easier for everyone to get help.

Healing Through Storytelling

Sharing stories is a powerful way to reduce the stigma around Alzheimer's. When families and caregivers talk about their experiences, they offer support and hope to others in similar situations. These personal stories help make the disease more real and easier to understand, changing how people view Alzheimer's. Music also helps tell these stories. Anthony Hamilton's version of "Stand By Me" brought peace to his family while caring for his grandmother with Alzheimer's, and Luis Fonsi's song "Girasoles" (sunflowers) is dedicated to his grandmother. Both songs are part of the Alzheimer's Association's Music Moments project to raise awareness and bring hope.

The Future of Alzheimer's Care: Shifting Attitudes

The future of Alzheimer's care depends on open conversations, understanding, and care that respects cultural differences. We can fight the negative ideas around Alzheimer's by educating people, reaching out to communities, and working together. Everyone—from individuals and healthcare workers to community leaders—needs to create safe spaces where Alzheimer's can be discussed openly without shame. This way, people with Alzheimer's can live with dignity, get the care they need, and share their experiences without fear of judgment.

Click here to access reference list.

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