



**Neurodegenerative
Disease Congress**



**ND Congress Pilot
Outcomes Report**

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Summary

Adira Foundation supports common goods and services—co-designed by people who use them and co-funded by a diverse alliance of people and entities driven to invest in better lives for people dealing with neurodegenerative diseases.

This year, Adira’s **fourth round of competitive grants** will undergo top-to-bottom design through the Neurodegenerative Disease (ND) Congress.

Through the ND Congress, Adira gathers people with **lived expertise** in congress with those with **professional expertise** to build appealing, viable, sustainable solutions to common, seemingly intractable problems.

Adira launched the series with a two-day virtual congress event where 16 people living with ND as well as caregivers, shared their lives and experiences as well as the concerns that they hold in common with one another. They discussed issues in real time alongside 13 people, who in one way or another, work on solutions. We have bucketed, for now, their thoughts into **eight priority areas**:

- 1 navigation support
- 2 caregiving
- 3 mental health support
- 4 inclusion of perspectives of people living with ND and caregivers in programs
- 5 better technology
- 6 access to research and education
- 7 convening multiple groups to work on solutions together
- 8 financial assistance

Participants also conceptualized solutions to two: **navigation support** and **mental health support**.

Explicit asks for **navigation** included to:

- ▶ “Have more navigators”
- ▶ “Have more patient & caregiver advocates”
- ▶ Offer peer-to-peer mentor programs
- ▶ Offer road maps early in the disease journey, to help guide what’s coming next
- ▶ Design resource maps and tools

Suggestions for **mental health** included:

- ▶ Build awareness among providers to ask about mental health and to treat it
- ▶ Reduce friction in connecting with mental health or related external services
- ▶ Offer more comprehensive care at medical facilities
- ▶ Address the shortage of mental health providers
- ▶ Frame as “total health,”—mental health integrated, complemented or concurrent with physical health

None of these terms or categories are fully final. They are only the starting point for people most impacted guiding the direction in an ongoing, vibrant way. We will put pencils down on what the next round of grants looks like—in terms of categories, terms, inventive ideas—after the next event in the ND Congress Series.

ND Congress Series Timeline

LISTEN

Pilot

Virtual | 1/20 - 1/21
Discover Needs

LEARN

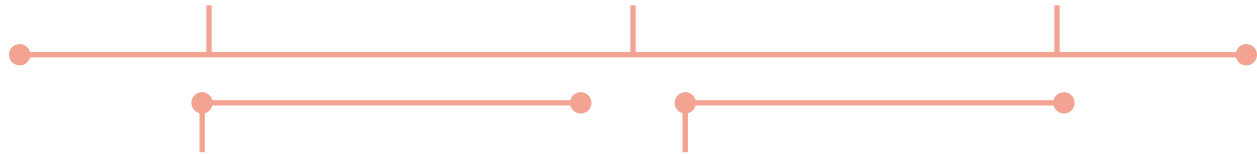
Extended Pilot

Denver, CO | 6/16 - 6/17
Finalize Solutions

ACT

ND Congress

Washington, D.C. | 11/17 - 11/18
Implement Solutions



Teams Form | February - June
Teams create viable grants

- Build teams to volley potential solutions and use evidence to build and grow these informed solutions
- Invite and recruit an evergreen alliance of people living with ND, caregivers and professionals to participate in part two of the ND Congress series and beyond

Teams Advance | June - November
Teams finalize grants and impact metrics

- Prioritize between three and five programmatic ideas for funding
- Set markers and metrics to best monitor and evaluate impact
- Ask people to bring forth their best strengths to see this plan of action through

Much of the help that exists for people with complex health is essential, but still limited—silos by disease state or other narrow categories. Adira aims to take diseases out of isolation—starting with ALS (amyotrophic lateral sclerosis), Alzheimer’s disease and related dementias, Huntington’s disease, multiple sclerosis and Parkinson’s disease—for a wider view of common goods and services that address shared issues too big to tackle alone.

Adira invites people and organizations to come together to share, prioritize and fund needs, guided by the people most impacted by neurodegenerative diseases (ND)—those living with them and caregivers.

“At Adira we ask people what they need but aren’t getting, then fund what’s most important to them in easier ways they can find and use. The ND Congress series let’s us not just consult with people at the middle and end of the grantmaking, but from the start.”

Greg Smiley
CEO & Founder of Adira Foundation

Purpose

The purpose of the Congress is to collaboratively improve our grantmaking—from the very beginning of the grant cycle—deploying three core Adira commitments. We will do so by building common goods and services which are co-designed by people most impacted by ND as well as co-funded by a diverse, wide-ranging alliance of people and entities driven to invest in better lives for people with ND.

Our goal is to reveal new grants for qualified non-profits which address those common, tougher problems that seem too large for any one group to own.

The Pilot ND Congress was the first in a series to design new help for people impacted by ND from their point of view. In each conversation, people with lived expertise share and create solutions in congress with those with professional expertise to make those solutions viable. We anchor the series under three tentpoles:

LISTEN The first event is to **listen** for which common needs seem to rise to the top and what better help might look like. Then teams form—again composed by those who receive services alongside those who provide services. Teams volley and co-design services to consider in congress in June.

LEARN The second event in June is for **learning** which options rise to the top for appeal, viability, and sustainability.

ACT The series culminates in **acting**. We reveal the three to five finalized grant opportunities and how much money we have raised to fund them. At this November event, we concurrently prepare for an even stronger Round 5 of grants.

“I believe in people working together as a team ... because together, let me tell you, we can become super powerful. And what Adira has done is what no other organization that I’m aware of has done is to pull all the different neurodegenerative diseases together, because in my opinion, they do fall under one umbrella.”

Person living with Alzheimer’s

What do people impacted by ND say they need but aren’t getting?



How do they want to get it?



How can we fund and implement these solutions?

Attendee Demographics

We sought to listen and learn from people representing some diversity in geography, identity, age and more about life from their point-of-view. The majority of congress participants were people living with ND and their caregivers. Here is some of what they represented:

51% or more of attendees are people with 1 of the 5 target diseases and/or their caregivers

8 People of Color

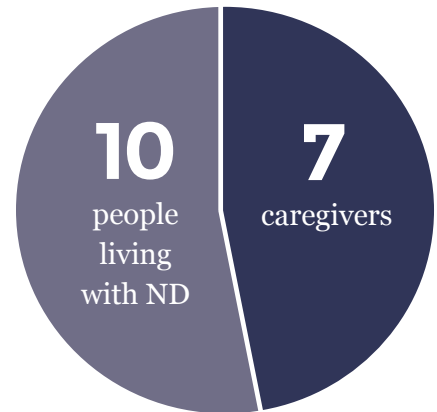
9 White



9 Female



8 Male



35%

Alzheimer's disease & related dementias

18%

ALS

6%

Huntington's disease

35%

Multiple sclerosis

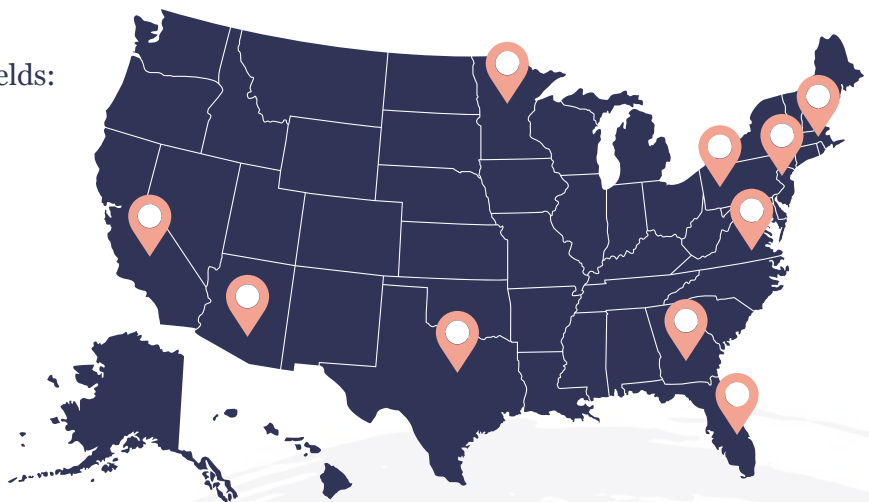
6%

Parkinson's disease

(Note: Some people are impacted by more than one ND. This may be a person living with an ND while acting as a caregiver for another person with ND, or a multi-caregiving role for two or more people living with ND. These situations are not reflected in these charts.)

The professional groups in attendance included a range of fields:

- ▶ Advocacy organization
- ▶ Life science groups
- ▶ Foundations
- ▶ Public health universities
- ▶ Government agencies
- ▶ Nonprofit health-related organizations



Get to Know a Few Attendees

MARIA



Maria is a neurologist and patient herself, but identifies as caregiver, having cared for several family members.

She's from a small town in Texas called Nacogdoches. "I like to call it Naco-Nowhere," she says.

"I really enjoy painting and coloring, especially when I do them with my daughter."

JIM & GERI



Jim is currently in Jupiter, Florida where Geri, who is from Manhattan, is visiting for four months.

When asked about her hobbies, Geri said, **"it's my photography from years back to childhood."**

"While I'm down here, my hobby is really trying to **swim every day**, which is wonderful." *-Jim*



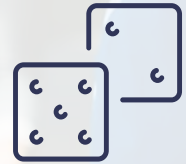
DARY



Although Dary has lived in New York for over 30 years, she is originally from Uruguay, South America.

"Well, it's sad, but my hobbies were dancing and things like that. So I'm **down to just listening to music** right now because I can't do much dancing."

RHONDA



Rhonda lives in Minnesota.

"One of the hobbies I **really enjoy and it's how I met my husband** is the good old fashioned roleplay games with dice and pencil and paper—think Dungeons and Dragons."

VICKIE



Vickie lives in Marietta, Georgia.

"I love to golf when I can, which isn't very often. And I like to read."

Adira's Work

Adira staff and grantees shared some of Adira's work to date as a starting point:

- ▶ An Alzheimer's caregiver shared his reflections on keeping the person living with a disease in mind during care delivery
- ▶ Adira CEO Greg Smiley told the story of Adira's model, inspired by successful large-scale integrated health programs on common problems such as the Global Fund to Fight AIDS, TB, & Malaria
- ▶ George Washington University Associate Research Professor Naomi Seiler presented research findings from a case study of three programs that have shown success in the transformation of care and services for people living with HIV to inform Adira's efforts for people with neurodegenerative diseases
- ▶ Adira Programs Manager Lauren Ruiz overviewed Adira's listening work and granting to date
- ▶ A panel of people living with a neurodegenerative disease and caregivers discussed what quality of life means to them

A Poem about Alzheimer's

Do not ask me to remember.
Don't try to make me understand.
Let me rest and know you're with me.
Kiss my cheek and hold my hand.

I'm confused beyond your concept.
I am sad and sick and lost.
All I know is that I need you
To be with me at all cost.

Do not lose you patience with me.
Do not scold or curse or cry.
I can't help the way I'm acting,
Can't be different 'though I try.

Just remember that I need you,
That the best of me is gone.
Please don't fail to stand beside me,
Love me 'till my life is done.

- Unknown

Poem shared by Alzheimer's caregiver

"I'm used to being in a lot of groups where all we talk about is things related to dementia, but I am really grateful that I had the opportunity to be a part of this ... It's been so great to hear another side of not just the dementia world, but how other people across the spectrum of neurology are impacted. And to see that we have so much in common. In a way, it breaks my heart to see some of this, but I think stronger together we can accomplish a lot more.

Person living with Alzheimer's

GUIDED CONVERSATIONS:

Quality of Life

Most of the two-day event was guided conversation. At the first talk, participants volleyed the potential of a standardized “quality of life” index.

- ▶ What do you want more of?
 - ▶ Interventions that give more **time** for that which matters to you?
 - ▶ More **money** in your bank to relieve financial burdens of disease?
 - ▶ More physical and mental energy to be able to take on each day?
 - ▶ More **confidence** to navigate systems and make decisions?
 - ▶ More **connection** to yourself and to others for support?
- ▶ Do programs exist that can deliver the outcomes most important to you?
- ▶ What types of programs would you like to see more funding for?

When I moved here [for family help with caregiving], I became super sedentary. And my kids get me out to camp with them because they know that Dad can start a fire, and Dad can chop wood, and Dad probably has the only tent. So I've been included a lot. And that's great. But I lost a lot by leaving my work as a ranch hand. And I'm probably still grieving about that to some level, but I did gain an awful lot to have the daughters nearby.

Caregiver to spouse with Alzheimer's; Lives with Parkinson's

Our first meeting with [a representative from an ALS group], they gave my husband a knife, a spoon and a fork. And that meant everything because it meant that he could still feed himself and he still had life to live. It was the first time that somebody said that you're not dying tomorrow. And then every other meeting, they kept saying, no, you're living today.

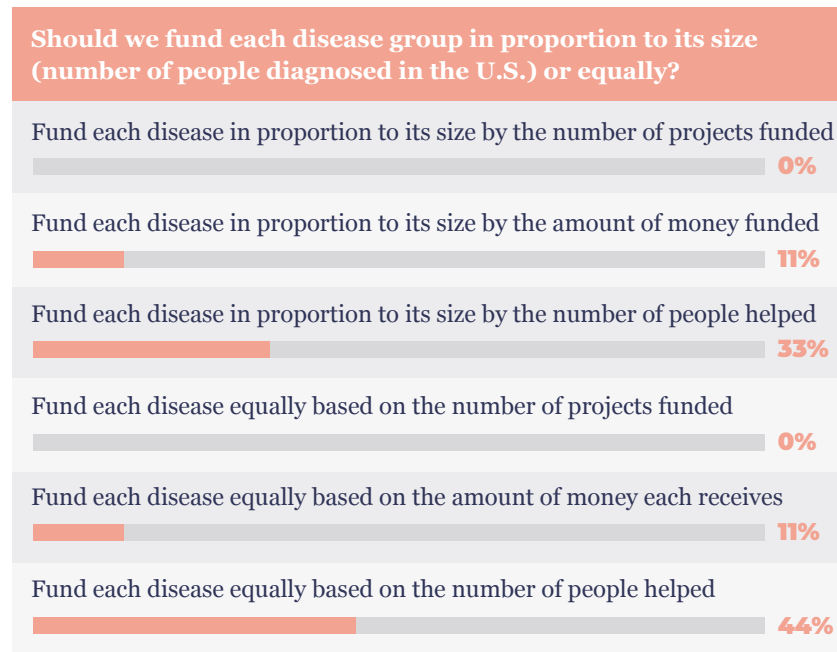
Caregiver to husband with ALS

Once a person is diagnosed with Alzheimer's, all they have is hope. And that's what the caregiver has is hope. Hope that a cure can be found, hope that the progression can be slow, or hope to ease the symptoms. I feel clinical trials provide that hope.

Caregiver to spouse with Alzheimer's

POLL: Grant Distribution

This poll prompted discussion about how to fund five diseases together. Some reactions:



I really want to make sure that as we listen, as we look to act and grant funds to organizations, that those things that you are communicating to us aren't being lost in translation.

Lauren Ruiz, Programs Manager, Adira

I'm not sure equity comes to mind when I think of funding these diseases. It's need. It's where's the lack of funding. I suspect Huntington's is not at the top of everybody's list, and the needs may be greater than in Alzheimer's, which is getting lots of publicity. Believe me, I want more funding. But the problem with that is it's much easier to have a formulaic approach than to be the Zeus to decide who has the greatest need, because we all think, of course, we're the most needy.

Jim Taylor

GUIDED CONVERSATIONS:

Priorities Named

The next guided conversation was spent naming problems that often come up for people and then to see which are common amongst the diseases.

What should Adira fund? Name common issues or challenges you'd like to see addressed.

Participants named needs that fell into eight primary categories:

- 1 CARE NAVIGATION SUPPORT**
- 2 CAREGIVING**
- 3 MENTAL HEALTH SUPPORT**
- 4 INCLUSION OF PERSPECTIVES OF PEOPLE LIVING WITH ND**
- 5 BETTER TECHNOLOGY**
- 6 ACCESS TO RESEARCH & EDUCATION**
- 7 CONVENING GROUPS TO WORK TOGETHER ON SOLUTIONS**
- 8 FINANCIAL ASSISTANCE**

GUIDED CONVERSATIONS:

Priorities Named Continued

1 CARE NAVIGATION SUPPORT

- ▶ More navigators (insurance, jargon/knowing how to communicate needs)
- ▶ More patient and caregiver advocates
- ▶ Peer-to-peer mentor programs
- ▶ Resource maps and tools

2 CAREGIVING

- ▶ Household skills

Caregiver support ... is a really big one, both for the health and wellbeing of the caregiver and then, of course, indirectly for the health and wellbeing of the patients. So it's really thinking about not just sort of, get people drugs, make sure people have insurance, but thinking broadly about: What are those unmet needs that insurance probably doesn't cover but that are so important to people's wellbeing?

Professional, academics

You're taking care of the person with Alzheimer's 24 hours per day, 365 days a year. Things can go wrong at any time. People that have dementia, it's not their fault when things go wrong, but it can go wrong.

Caregiver to spouse with Alzheimer's

GUIDED CONVERSATIONS: **Priorities Named Continued**

3 MENTAL HEALTH SUPPORT

- ▶ Feelings of loneliness, isolation (physical/mental), anxiety, depression, fatigue (mental/physical), guilt, mourning, grief.
- ▶ Losing work, and with that identity, sense of purpose or pride.
- ▶ Need for support, acknowledgment, validation, etc.
- ▶ Caregivers rebuilding after death of loved one—loss of support.
- ▶ Need to mentally prepare to deal with providers that resist, undercut, battle, etc.

I think all of us have been hit as a caregiver, as a patient, we've all experienced these raw emotions, this feeling of hopelessness, helplessness, frustration, happiness. What do I do with my life now? Why me? All those things.

Caregiver to family with Parkinson's; Lives with Parkinson's



4 INCLUSION OF PERSPECTIVES OF PEOPLE LIVING WITH ND

5 BETTER TECHNOLOGY

- ▶ Diagnostic
- ▶ Day-to-day help

GUIDED CONVERSATIONS: Priorities Named Continued

6 ACCESS TO RESEARCH

- ▶ Financial and other barriers (transportation, lodging)

There's not enough knowledge. Sometimes even now I could go to a medical facility and tell them, my husband has ALS, and they'll look at me like, 'What's that?' And within the black community there's none. There's none. So it would be nice to be able to educate people about the different forms, like Parkinson's."

Caregiver to spouse living with ALS

I have probably spent as much time educating medical staff about [multiple sclerosis] as I have the general public. The fact that there are different varieties of MS, and that MS is different from ALS or Huntington's, there is a horrendous lack of education.

Person living with multiple sclerosis

7 CONVENING GROUPS TO WORK TOGETHER ON SOLUTIONS

- ▶ Convening industry, providers, insurance, patients, caregivers, etc. to work on issues together

8 FINANCIAL ASSISTANCE

- ▶ Medicine
- ▶ Transportation

[Another service] was like, 'We can help everybody, just give us a call.' And then there's like 17 reams of paperwork that I don't even understand that need to be filled out or gone through or to make sure that you're qualified. And it's just like, OK, forget it. I'm going to go make some oatmeal, because it's just overwhelming to find real resources."

Caregiver to parents with Alzheimer's

"I'm not looking for a pat on the back. I'm looking for someone to come in and say, 'I understand what you're facing, and here are some of the things you can do—no, I'm sorry—here are some of the things I can do to help you with what you're doing.'"

Caregiver to spouse with Alzheimer's; Lives with Parkinson's

GUIDED CONVERSATIONS: Solutions

DESIGNING SOLUTIONS

Participants split into two breakout rooms based on the needs identified that rose to the top—navigation and mental health—and shared solutions they would like to see Adira and others fund.

NAVIGATING SOLUTIONS

1. Have more navigators.
 - ▶ Navigators are assigned and consistent.
 - ▶ Offer access to a network of people—those that care, share and deliver.
 - ▶ Navigators are trained in insurance, jargon, and how to communicate needs.
2. Have more patient and caregiver advocates.
 - ▶ Advocates are assigned and consistent.
3. Offer peer-to-peer mentor programs.
4. Offer road maps early in the disease journey, to help guide what's coming next
5. Design resource maps and tools.
 - ▶ Decision-tree processes including what questions to ask, what information to know upfront.
 - ▶ Technology (answers most of the questions) + direct support (more guidance and one-on-one help).

Other ideas:

- ▶ Topics that need better navigation: clinical trials, research, caregiver resources, treatment resources.
- ▶ It's not about telling people what they need, it's about helping them with what they need.



All of these resources that are being thought of and potentially developed, all these tools, these toolboxes that we're trying to build. There will be no one single solution for everything. But as long as we include the patient experience, we will hit the mark.

Person living with ALS

We all have a neurologic disease, which means that our intellectual capacities are sometimes affected more so than others at times, along with our energy levels and other problems, which means that getting through all these roadblocks is even more challenging when you're not thinking right. So, we need an advocate. We need somebody that we can talk to that will be able to step up or guide us or do it when we need that help.

Caregiver to family with Parkinson's; Lives with Parkinson's

Key Insights

For Adira, the ND Congress inspired many different feelings, ideas, and reflections. We hope if you are reading this and feeling similarly inspired that you will sign-on to a work team, join us at an upcoming ND Congress event, become a part of our Sounding Board, or reach out to learn how you can support Adira or the communities we serve in other ways.

▶ **We heard personal stories emphasizing the need for help now. And for that help to be offered in ways that reduce stress, not add to it.**

We celebrate the benefits of hope for medical treatments or cures, but we also understand that millions of people need help today, or even yesterday. The stories we heard emphasized real concerns about the mental health impacts of isolation, financial stress, grief, and burnout. Many of the frustrations shared centered around the maze-like nature of finding resources for support – and the indispensable time and energy often wasted trying to navigate it all alone.

We also heard many positive experiences people living with ND and caregivers have had. Most importantly, the ways these experiences made them feel. We look to harness these best approaches to help identify solutions that will have the biggest impact for people living with ND and caregivers right now.

▶ **We believe that people living with ND and caregivers have the right to define what quality-of-life means for them.**

It's hard to find a one-size-fits-all solution. For example, we heard that technology can be a benefit in many situations but can create additional challenges in others. This is an important lesson to remember as we look to evaluate programs for people most impacted by ND. We must make sure people living with ND and caregivers are seeing the outcomes that are most important to them and their definition of quality-of-life.

As we co-design what ideal solutions look like with people living with ND and caregivers we will continue to discuss and hear how those solutions would improve quality-of-life. We want to elevate these perspectives and share them with the network of organizations involved in ND care that fund, deliver and evaluate programs for people most impacted.

▶ **We recognize the power of a broader community of people working to solve common problems.**

We know it takes a lot to create real impact on a grand scale for ND communities. It takes a commitment from many different groups working together to make big change – health care providers, advocates, funders, nonprofits, and more. That's why we're bringing more people into the conversation.

By leveraging each of our strengths and combining our collective knowledge we can create, together, a real plan of action. One that is guided by the priorities and real-life perspectives of people living with ND and caregivers and can strengthen the safety net for everyone.

Stay Involved

Click the buttons below or email programs@adirafoundation.org to ask us how to:

Join a team

Attend an ND Congress event

Comment on the report

Speak your mind through the Sounding Board

Disease Basics

AMYOTROPHIC LATERAL SCLEROSIS (ALS)

No muscle nourishment

ALS is a progressive neurodegenerative disease that affects nerve cells in the brain and spinal cord, weakening muscles and impacting physical function.

Not all people with ALS experience cognitive decline, though some do. Frontotemporal dementia (FTD) is a form of dementia that some people living with ALS may also be diagnosed with.

- ▶ Symptoms typically begin between ages 55 – 75
- ▶ Life expectancy is 2 – 5 years
- ▶ 5% of people with ALS may live 20 years or more after diagnosis

Symptoms vary from person to person, but could include:

- ▶ Muscle twitching in arms, legs, shoulders, and tongue
- ▶ Muscle cramps, tight or stiff muscles, and muscle weakness
- ▶ Slurred or nasal speech
- ▶ Difficulty chewing or swallowing
- ▶ Weight loss
- ▶ Depression and anxiety
- ▶ Trouble speaking or forming words
- ▶ Trouble breathing
- ▶ Inability to stand or walk
- ▶ Loss of use of hands and arms

All definitions are from the National Institute of Neurological Disorders and Stroke.

Disease Basics Continued

ALZHEIMER'S DISEASE & OTHER DEMENTIAS

Degeneration of the brain

Alzheimer's disease is an irreversible, progressive brain disorder that slowly destroys memory and thinking skills and, eventually, the ability to carry out the simplest tasks.

It is the most common form of dementia. Forms of dementia related to Alzheimer's disease include frontotemporal dementia, Lewy Body dementia, and vascular dementia.

- ▶ Symptoms typically begin in a person's mid-60's
- ▶ Life expectancy is 8 – 10 years
- ▶ People diagnosed over the age of 80 live on average 3 – 4 years after diagnosis

Symptoms vary from person to person, but could include:

- ▶ Memory loss
- ▶ Progresses from loss of short-term to long-term memories
- ▶ Difficulty recognizing familiar people
- ▶ Difficulty learning, confusion
- ▶ Confusion of past and present
- ▶ Trouble communicating
- ▶ Difficulty speaking, writing, reading
- ▶ Loss of energy and spontaneity
- ▶ Mood swings, irritability, anxiety, depression
- ▶ Physical or verbal outbursts
- ▶ Sleep disturbances
- ▶ Hallucinations, delusions
- ▶ Restlessness, pacing, shredding items
- ▶ Loss of control of bodily functions

All definitions are from the National Institute of Neurological Disorders and Stroke.

Disease Basics Continued

HUNTINGTON'S DISEASE (HD)

Degeneration of the nerve cells in the brain

HD is a fatal genetic disorder that causes progressive breakdown of nerve cells in the brain, deteriorating physical and mental abilities. It is considered a 'family disease' as every child of a parent with HD has a 50/50 chance of inheriting the disease.

- ▶ Symptoms typically begin between the ages of 30 – 50
- ▶ Life expectancy ranges from 10 – 25 years
- ▶ 17 years is the average length of disease progression before death

Symptoms vary from person to person, but could include:

- ▶ Difficulty thinking through problems
- ▶ Changes in thinking and reasoning abilities
- ▶ Irritability, depression
- ▶ Weight loss
- ▶ Chorea (uncontrollable movements)
- ▶ Diminished speech
- ▶ Difficulty swallowing
- ▶ Loss of ability to walk

All definitions are from the National Institute of Neurological Disorders and Stroke.

Disease Basics Continued

MULTIPLE SCLEROSIS (MS)

Inflammation leading to multiple areas of scarring

MS is an unpredictable disease of the central nervous system that disrupts the flow of information between the brain and the body.

- ▶ Symptoms typically begin between the ages of 20 – 50
- ▶ MS is considered ‘non-fatal’
- ▶ Life expectancy is about 7 years less than the general population

Symptoms vary from person to person, but could include:

- ▶ Blurred or double vision
- ▶ Pain and loss of vision
- ▶ Weak, stiff muscles
- ▶ Painful muscle spasms
- ▶ Tingling or numbness in arms, legs, trunk, or face
- ▶ Clumsiness, difficulty balancing and walking
- ▶ Bladder control difficulty
- ▶ Mental and physical fatigue
- ▶ Mood swings from depression to euphoria
- ▶ Difficulty concentrating, making decisions, planning

All definitions are from the National Institute of Neurological Disorders and Stroke.

Disease Basics Continued

PARKINSON'S DISEASE

Degeneration of dopamine-producing neurons

Parkinson's disease predominantly affects dopamine-producing neurons in a specific area of the brain called substantia nigra.

- ▶ The average age of diagnosis is 60
- ▶ More than 90% of people diagnosed with Parkinson's are 50 years or older
- ▶ Life expectancy ranges from a few years to several decades, with an average of about 16 years

Symptoms vary from person to person, but could include:

- ▶ Tremors
- ▶ Changes in posture
- ▶ Slowness of movement
- ▶ Difficulty walking
- ▶ Loss of balance
- ▶ Difficulty chewing
- ▶ Difficulty speaking
- ▶ Urinary problems
- ▶ Hallucinations, delusions

All definitions are from the National Institute of Neurological Disorders and Stroke.

Thank You Congress Sponsors

Thank you to our ND Congress Corporate Sponsors for their commitment to people living with neurodegenerative disease and caregivers.



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