



BEYONDD

Biomarker Evaluation in Young Onset
Dementia from Diverse Populations

Understanding Brain Health and Aging through BEYONDD

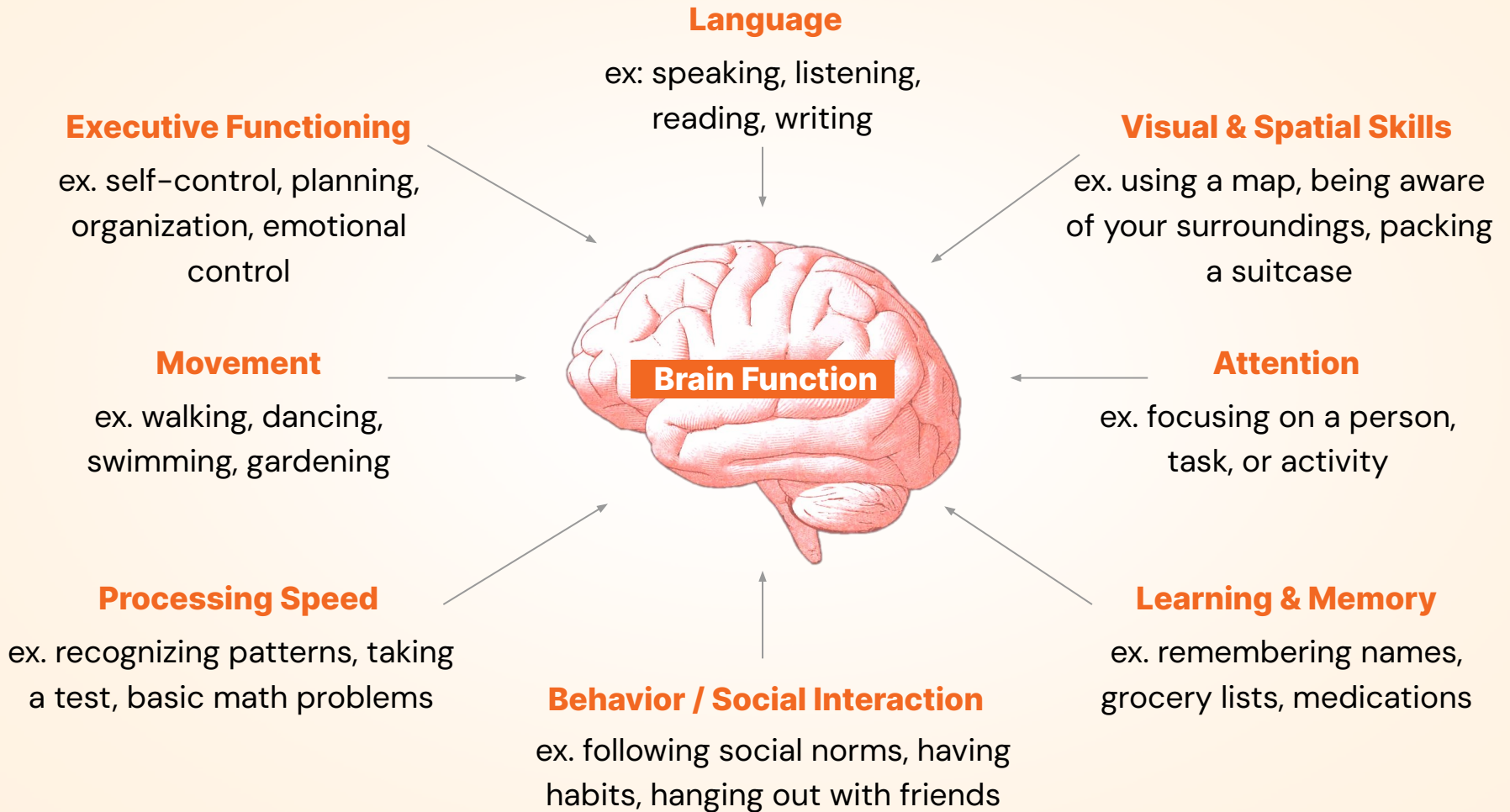




BEYOND DD

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Part 1: Introduction



Brain Function and Aging



- Different areas or networks of the brain are responsible for different brain functions
- Some changes in brain function are a **normal** part of aging, like:
 - slowed thinking
 - occasional memory difficulties
- Changes that are sudden, severe, or impact your daily life may not be a normal part of aging

Other Changes

- Changes in behavior, habits, or personality may also be signs of brain health problems
- If you notice changes that you think might be related to your brain health, it is important to talk to your doctor about them



What is Dementia?



Common causes of dementia include these brain diseases.

Frontotemporal
Dementia
(FTD)

Alzheimer's
Disease

Parkinson's
Disease

Vascular
Dementia

and others...

- **Dementia is not one single disease** – it is an 'umbrella term' that means that *changes in brain function are interfering with your day-to-day life*
- **Early Onset Dementia** is when you have dementia before age 65
- These conditions may cause changes in:
 - Thinking
 - Memory
 - Behavior
 - Personality

What else could be causing these changes?

Recent changes in your thinking skills, memory, or mood can be caused by any combination of the following factors:

General health problems

(ex. not enough Vitamin B12, medication side effects, hormone imbalance)

Dementia-causing diseases

(ex. FTD or Alzheimer's)

Other brain diseases

(ex. stroke or depression)

Unknown causes



- There is no one test to determine the cause of these recent changes
- Multiple factors may be at play at the same time



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Part 2:

What can you learn from BEYONDD?

What Can You Learn from Your Results?

	At-Home Only Visits	Research Center Visits
What results can I learn about?	<ul style="list-style-type: none"> • Standard Labs • Blood Biomarkers • Online Tests of Thinking and Memory 	<ul style="list-style-type: none"> • Standard Labs • Blood Biomarkers • Tests of Thinking and Memory • <i>On-site</i> Tests of Thinking and Memory • <i>On-site</i> MRI scan
Where will this visit take place?	Via videoconference	At the study site or via videoconference
Visit overview	<ul style="list-style-type: none"> • You will get a 1-on-1 session with a BEYONDD expert • Your results will be big picture – BEYONDD will not give you a diagnosis 	<ul style="list-style-type: none"> • You will get a 1-on-1 session with a BEYONDD expert • Your results will be big picture – BEYONDD may provide you with a diagnosis you can share with your doctor
Potential trade-offs	<ul style="list-style-type: none"> • No MRI scan • No in-depth tests of thinking and memory 	<ul style="list-style-type: none"> • Site visit is less convenient than an at-home disclosure



Meet Vanessa...

- She hasn't been acting like herself lately
- Recently she noticed:
 - She's having trouble staying organized at work
 - She's made some bad financial decisions that she wouldn't have done in the past
- She saw an ad online for the BEYONDD project and decided to take control of her brain health

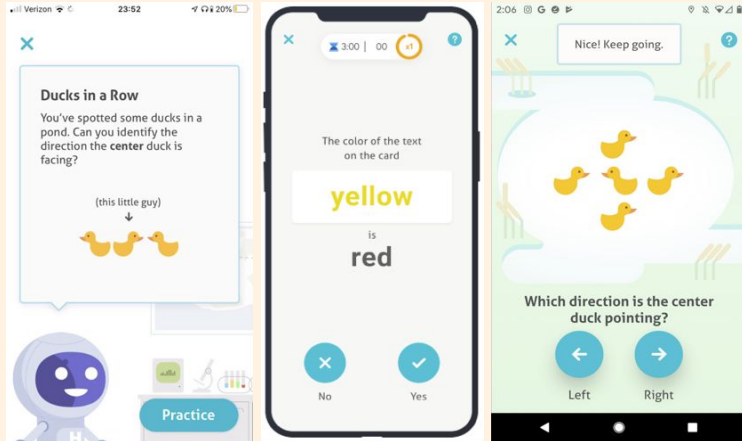
She was eligible!

- After taking the short eligibility survey, Vanessa decided she wanted to see what BEYONDD had to offer
- First:
 - She went online and filled out a series of short questionnaires from her tablet at home
- Then:
 - She scheduled an at-home visit to take some online tests of thinking and memory and get her blood drawn



What are tests of thinking and memory?

Process: You complete short online tests of your thinking abilities from the comfort of your own home.



What can we learn from these?

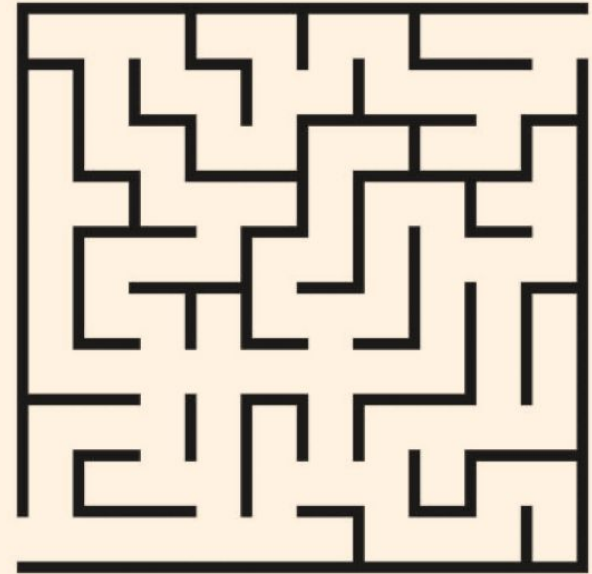
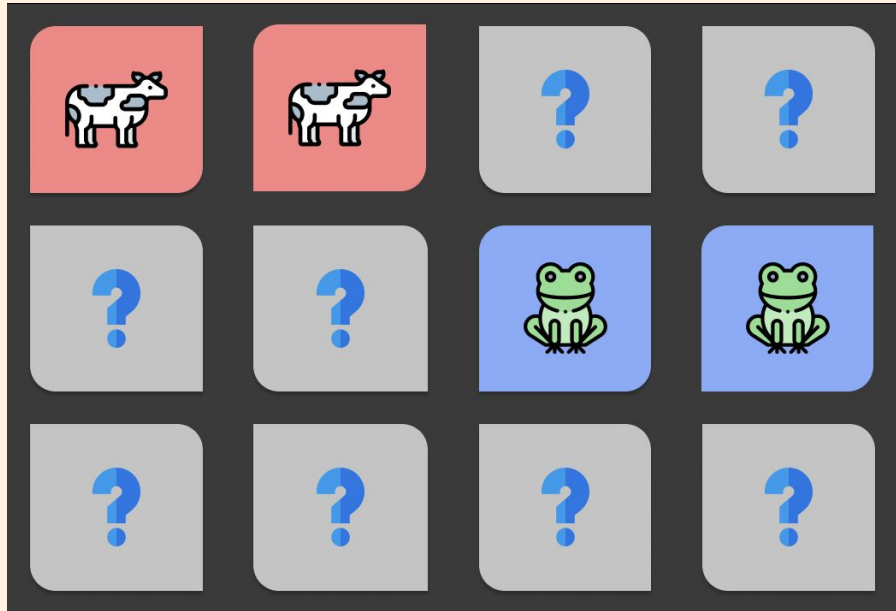
- Are your thinking abilities normal for your age?

How do we figure this out?

- Your results are compared to people of:
 - Similar age
 - Same gender
 - Similar educational background

The tests are short, like games

We test how well you can remember things like where a pair of cards is...



...or use your thinking skills like when you solve a maze

As part of BEYONDD, Vanessa got to learn her results

- Her results showed she had some problems with thinking speed and behavior
- Adults with brain health problems can have trouble on different areas of memory and thinking
 - Not all difficulties indicate that there's a brain problem

Area	Vanessa's Results
Attention	Within normal limits
Thinking Speed	Problem area
Language	Within normal limits
Visual & Spatial Abilities	Within normal limits
Learning & Memory	Within normal limits
Behavior	Problem area



BEYONDD won't just look at the results of only one test

- Brain health can be complicated
 - No one test can determine whether you have brain health problems
- As part of BEYONDD, Vanessa also had her blood drawn from the convenience of her own home
 - From this sample, important blood tests were run

What are blood tests?

Process: *You provide a blood sample from the comfort of your own home*



What blood tests do we do?

- Standard tests, like those done at a regular visit to your doctor
 - This helps us get a better picture of your overall health and may identify risk factors that you can do something about
- Experimental tests for causes of brain problems
 - This helps us determine the levels of changes in your blood that might be caused by brain disease.

What can we learn from your standard blood tests?

Standard lab tests can tell us if you have or are at increased risk for:

- Kidney or liver disease
- Heart disease
- Diabetes
- Stroke

They can also show if you have:

- A hormone imbalance
- Abnormal vitamin levels





What can you learn from experimental blood tests?

- Some brain diseases leave clues in your brain, like higher levels of proteins called amyloid and tau
- These proteins can be detected using blood tests not yet available to the public
- As a participant in BEYONDD you will have access to these tests

After her at-home visit...

- Vanessa was offered the opportunity to come into one of our expert centers
- If she chose to participate in **only** the online and at-home procedures, she could now schedule an online meeting to learn her results
 - Here she would meet 1-on-1 with an expert to discuss the results of her online and at-home visits



Vanessa decided she wanted to continue

- She wanted to learn more and decided to join us at one of our expert centers
- At the BEYONDD on-site visit, she:
 - Completed other tests of thinking and memory
 - Got to meet with a team of experts from our study
 - Had an MRI to show pictures of her brain



Brain MRI pictures

Process: *If you choose to come into one of our expert centers, study doctors will take pictures of your brain at one of our study sites*



What can we learn from MRI pictures?

- Whether there are any visible signs of brain disease

How do we figure this out?

- We will compare your pictures to pictures from:
 - Healthy adults
 - Adults with different brain diseases

Because Vanessa completed an at-home *and* on-site visit...

- She chose to learn about her brain and general health in his BEYONDD visit
- During her 1-on-1 session with a healthcare professional, she learned about her blood test and brain MRI results
- She also got a summary of her results to take home and share with her own doctor



Test Results: You choose what to share

Vanessa chose to learn the following:

Feedback option	Blood Biomarker	Tests of thinking and memory	Standard Lab Tests	Brain and Imaging
Share results?	[x]	[x]	[x]	[x]

Vanessa will have multiple opportunities to decide if/what she wants to learn and share and can change her mind at any time.

Looks like the study doctors had some concerns about Vanessa's standard labs and tests of memory and thinking results

	No Concerns	Some Concerns	Follow-up Needed
Standard Lab Tests			X
Blood Biomarkers	X		
Tests of thinking and memory		X	
Brain and Imaging	X		
Overall			X

Follow up with her primary care doctor was recommended to discuss these concerns

What if Vanessa's results had looked different?

	No Concerns	Some Concerns	Follow-up Needed
Standard Lab Tests	x		
Blood Biomarkers		x	
Tests of thinking and memory	x		
Brain and Imaging		x	
Overall		x	

- BEYONDD doctors had some concerns about Vanessa's blood biomarker and brain imaging results.
- Based on these results, they suggested she follow-up with a specialist instead of her regular doctor.

Vanessa shared her results summary with her doctor



BEYONDD empowered her to take control of her own brain health

- Her doctor was able to identify early signs of diabetes
- Vanessa was able to make changes to her diet and exercise to improve her health
- She was able to access cutting edge research tests and care at no cost



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Part 3: Risk & Benefits

What are some potential benefits of knowing your results?

You and your family can:

- *Talk to your doctor about:*
 - Understanding the possible causes of your thinking difficulties
 - Finding a specialist
 - Possible treatments if you develop symptoms
- *Join additional research or clinical trials*
- *Make changes to your lifestyle to protect your health, including diet and exercise*






What are some potential **benefits** of knowing your results?

Your results may help you decide:

- Your wishes for medical care
- Health or long-term care planning
- Who will make decisions for you if you cannot

Your results may also help your family support you in making:

- Employment/retirement decisions
 - Family planning decisions
- 

What are some potential risks of knowing your results?

- **Anxiety or worry**
- **Breach of confidentiality** (others finding out about your health problems)
- **Negative attitudes** from friends, family, or community members
- **Trouble** getting some kinds of insurance



Benefits

- Talking to your doctor about keeping an eye on your symptoms or possible treatments
- Taking part in research, including learning about studies with possible treatments
- Making healthy changes to your daily habits and routines
- Talking about your wishes with your family
- Making legal and estate plans

Risks

- Worry, fear, anger
- Your private information being shared without permission
- Possible negative responses from loved ones or community
- Discrimination related to long term planning, medical care, or the law

**If you have any questions, just call
1-866-7MYMIND to speak with a
member of our team!**

Remember that you can review these slides as much as you'd like and please consider sharing them in a discussion with loved ones.



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