



The Johns Hopkins Memory & Alzheimer's Treatment Center
and Alzheimer's Disease Research Center presents

Journey to Hope

A free virtual conference for caregivers

Thank you for virtually joining us on Saturday, November 14, 2020
to learn about the research and treatment of memory loss, and
coping tips to manage during challenging times.

You had the opportunity to “Ask the Expert” your questions about memory-
related disorders. Here are the Questions & Answers from the conference.

Panel Discussion: Coping and Resilience in Isolation

1. What can I expect in my relationship as my husband's condition declines? How do I deal with the grief associated with watching a loved one slowly slip away, especially when you're the sole care giver?

You don't mention the stage your husband is in now. He may eventually no longer recognize you. This is not always the case, but most often is. You will take on more of a caregiver role.

- Finding support for yourself is of utmost importance as his disease progresses. One of our panelists, Pam South, mentioned 2 books, “Ambiguous Losses” and “Loving Someone Who Has Dementia”, both by author Pauline Boss.
- Consider working with a therapist familiar with dementia-related illness. Stay connected to friends and family. Join a support group. Resources for emotional support can be found [here](#).

2. How should the family deal with patient's denial and agitation about their situation that they have no control over?

The best way to manage agitation is to “join their journey”. Listen. Try not to force the issue. Redirect conversations when needed, use reminiscence (old pictures, photo albums, etc.) to change the direction of the conversation. Engage them in an activity, take a walk, listen to music.

3. What can her loved ones do to communicate our love to our sister dying soon and seemingly incommunicative? How to communicate with patient who is almost impossible to understand?

Just be with them. Sit with them. Listen to music, tell stories, read to them. Comfort them, let them know you're there and that you love them. Sometimes words aren't necessary. Your presence and a gentle touch may be what they need most.

4. Strategies for encouraging patient to go to the bathroom and shower.

Showers can be threatening to patients. They feel vulnerable - imagine being undressed in a cold shower stall with water rushing at your face and not understanding why! At some point, consider changing to a sponge-bath or hand-towel bath. Keep the person partially clothed, uncovering only the parts that you are bathing. Keep the room warm, provide soft towels, play gentle music.

5. What tips can be provided to caregivers regarding managing severe dementia/Alzheimer's.

This is a very broad question. For more detailed answers, consider contacting the Alzheimer's Association HelpLine 1-800-272-3900. They are available 24 hours/day, 365 days/year.

6. Please provide information about care during the pandemic.

We have developed a list of resources for caring for a loved one with dementia during the pandemic. You can find it [here](#).

7. Best type of doctor for someone with Alzheimer's?

It depends on their training and years of experience. The Memory Center incorporates a multidisciplinary and collaborative model with neuropsychiatrists, neurologists and geriatricians.

8. We need implanted GPS trackers for those that wander. Please address this need.

Not sure what you mean by "implanted". There are many GPS tracking systems available today including jewelry (necklaces, bracelets, anklets, pins), shoes, phones, etc. The best one for your loved one depends on their need(s). We can't endorse any particular product.

9. I would like more information on how to get into the Hopkins Family Support program. Does my mom have to be a current patient at JHH for me to be a part of this? I take care of my mom with newly diagnosed Alzheimer's. Club Memory would be great for my mom.

Club Memory is open to all caregivers and patients in the early and moderate stages of dementia. They do not need to be a current patient at JHH. We meet the 1st and 3rd Wednesdays of the month from 2-3pm via Zoom. The link and further details can be found [here](#).

10. What is the resource Pam mentioned about grieving during the panel?

"Ambiguous Loss" and "Loving Someone Who Has Dementia", both by Pauline Boss

11. How do you explain to a young child that their grandparent has Alzheimer's?

It depends on the age of the child. But generally, let them know their loved one has a brain disease that affects their memory and makes it harder for them to do things. Assure them that their grandparent still loves them and let them know it isn't contagious. Talk about ways they can still be with their loved one and how they can help.

Ask the Expert: Constantine Lyketsos, M.D., MHS

1. What is cerebellum ataxia?

Cerebellar ataxias are rare degenerative diseases of a part of the brain called the cerebellum. They have been associated with dementia in many patients.

2. Please comment on Serotonin Syndrome. My wife is taking 5 meds, including Zoloft, Depakote, Seroquel and Remeron. Are certain combinations (these meds and/or others) more likely to produce Serotonin Syndrome?

While I can't comment specifically on the case of your wife, serotonin syndrome is a distressing clinical state with confusion, restlessness, and distress that can be very serious. Certain medication such as Zoloft and Remeron do increase the risk for it. But, typically, very high doses are necessary to produce it.

3. How do you know if side effects may be due to meds or the disease itself? What are some of the more common side effects that you have seen in patients, especially with namenda?

Generally speaking, the side effects associated with FDA approved medications are known and can be discussed with the prescribing physician or reviewed in consultation with the pharmacist. Knowing ahead of time what the common side effects are for medication, coupled with timing relationships between taking a medicine and side effects or a dose of medicine and side effects, can be helpful in deciding whether a problem is a side effect of medicine or resulting from dementia.

4. Have you heard of the Bredesen protocol? What are your thoughts?

I have heard of this protocol, which is focused on achieving good brain health as a way of preventing dementia. While it has not been tested experimentally and its risks and benefits are not well known, many parts of it make sense.

5. How am I able to tell if gait changes/balance issues are related to dementia vs. just old age? She will be 90 years old this month. At what point should I consider PT or gait training? She walks with a cane now but not outside due to chronic arthritis in her knees, feet and spine.

This sort of question is best answered by a treating or prescribing physician. I can't comment on an individual patient.

6. Does FTD have any effect on appetite? My loved one is constantly hungry and hyper-focused on the next meal.

Increases in appetite are frequently described in patients with FTD and are thought to relate to the loss of inhibitory controls in the brain. Typically, the best way of handling this is by limiting access to food to avoid weight gain.

7. Are medication adjustments recommended for each stage of the disease?

Medications in dementia patients are used to target/help particular symptoms. To the extent that the symptoms may change with the course of the disease, medication adjustments may be necessary. This is best discussed individually with the patient's prescribing physician.



8. Please describe the risk factors for developing Alzheimer's, such as genetics, long-term inflammation, herpes and others.

This is a very complicated question. Genetics certainly play a role in developing Alzheimer's disease with a small number of genes being deterministic meaning that individuals who inherit these "bad" genes will get the disease if they live long enough. But for 95% of patients there are several dozen genes involved each of which slightly increases risk of Alzheimer's. Inflammation is thought to be a risk factor for dementia as are multiple other variables such as lower education, chronic stress, sleep disorders, depression, use of certain substances, and many others.

9. What OTC pain relievers have been found to be useful for muscular and other aches and pains for people with dementia?

All over-the-counter pain relievers can be used safely with patients with dementia to alleviate muscular and other aches and pains for people with dementia. Patients and families should follow the directions on the bottle and consult with their physicians regarding interactions with medication they may be prescribed.

10. Will Rivastigmine patches assist with curing the effects of brain damage caused by unsuccessful neurosurgery?

I would not expect rivastigmine to cure the effects of brain damage caused by unsuccessful neurosurgery.

11. When will it be safe to pursue long-term dementia care considering the COVID pandemic and how easily spreads in elder care facilities?

When the pandemic subsides, there should be opportunities to pursue long-term care as before the pandemic.

12. Please discuss neural synaptic spread in long time marijuana smokers.

I don't have information that would help me answer this question.

13. Are there any scans available that someone in their late 50's could do to see if they are developing amyloid plaques?

It is possible to use special PET scans to look for amyloid plaques in the brain of people at any age. However, these are research scans and are not recommended for clinical use.

14. Any connection between caffeine use and dementia?

The information is contradictory with some of it suggesting that caffeine use can impact risk of dementia by decreasing it.

15. I believe my husband is in stage 4/5, would he still be considered a candidate for a new drug if one becomes available soon?

I'm afraid I cannot comment on specific patients or make drug recommendations for patients I have not seen.

16. Is there any relationship between sleep apnea, vision and hearing problems and Alzheimer's disease?

Sleep apnea, vision loss, and hearing loss are all risk factors for Alzheimer's disease. While correcting them would probably reduce risk, it is unclear whether correcting them would fully eliminate risk.

Journey to Hope 2020 Agenda

9 a.m.

Welcome: Conference Overview and Goals

Constantine Lyketsos, M.D., MHS

*Director, Johns Hopkins Memory & Alzheimer's Treatment Center;
Director, Department of Psychiatry and Behavioral Sciences, Johns Hopkins Bayview*

Introduction of Patient-Family Advisory Council

Andrea Nelson, MSN, RN

*Director, Memory Care Programs, Johns Hopkins Memory & Alzheimer's Treatment Center
Director, Patient-Family Advisory Council*

9:10 - 9:30 a.m.

Update on Alzheimer's Care and Research

Sevil Yasar, M.D., Ph.D.

9:30 - 9:40 a.m.

Q&A with Dr. Yasar

Moderated by Andrea Nelson, MSN, RN, and Jennifer Mason, MSN, RN

9:40 - 9:45 a.m.

Break

9:45 - 10:30 a.m.

Panel Discussion: Coping and Resilience in Isolation

Moderated by Andrea Nelson, MSN, RN, and Jennifer Mason, MSN, RN

Janet Michel, Caregiver and Patient-Family Advisory Council Member

Pam South, Caregiver and Patient-Family Advisory Council Member

Yolanda Wright, MSW, Alzheimer's Association

Jessica Young, Ferretto Eldercare Consulting, Inc.

10:30 a.m.

Presentation of Awards (pre-recorded)

Caring Hands Award – Presented by Jane Marks, MS, RN, Johns Hopkins Geriatric Workforce Enhancement Program

Trailblazer Award – Kathy Rostkowski, Memory Center volunteer

Trailblazer Award – Tyrone Qualls, MACAB president

Pioneer Award – Reba Cornman, MSW

10:45 - 11:30 a.m.

Ask the Expert

Constantine Lyketsos, M.D., MHS

11:30 a.m.

Closing Remarks

Constantine Lyketsos, M.D., MHS

Call to Action

Mary Ann Esfandiari and Helen Hovdesven

Co-chairs, Memory Center Patient-Family Advisory Council

