



Caregiving and Psychological Issues

This program speaks about the different symptoms and stages associated with Alzheimer's disease. In addition, the program features a discussion of best practices associated with caring for an individual during the course of the disease.

JON MERRIL: Alzcast.org, providing a powerful resource for doctors, nurses, and care givers coping with the impact of Alzheimer's disease. In today's podcast we explore care giving and psychological issues associated with Alzheimer's disease. We are honored to have Peter Rabins, MD, and Masters in Public Health to discuss this topic with us. Dr. Rabins is professor of psychiatry and behavioral sciences at the Johns Hopkins University School of Medicine. Dr. Rabins is also on the senior faculty of the Copper Ridge Institute and has written numerous articles on Alzheimer's disease including the best-selling book entitled [The 36-Hour Day: A Family Guide to Caring for Persons With Alzheimer Disease, Related Dementing Illnesses, and Memory Loss in Later Life](#). The first question for Dr. Rabins is how does care giving change during the different stages of Alzheimer's disease?

PETER RABINS: Sure. It's important to say at the beginning that there's not one right pattern, right way to do things, but I think some generalizations can be made. The way I approach the disease is to break it into three stages, each lasting about three years. On the first stage memory is the dominant problem area. In the second three year stage people begin to develop problems with communication, doing everyday activities like brushing your teeth, feeding themselves, etc., and perceiving the world. And then the third stage is when people start having physical decline and start having difficulty walking, feeding themselves, etc. And so care giver needs are different at each of these stages. I think at the first stage, first of course we want to make sure that people have had the proper diagnosis. But at the first stage it's important to keep the person active and busy and for the caregiver to realize that many of the frustrations that she or he is facing relate to the frustrations brought on by the person's forgetfulness, the fact that the person with the disease will repeat themselves, that the caregiver therefore has to say things repeatedly, that the care giver has to adapt to the fact that the relationship has changed and that the care giver has to take over the rolls of things that the ill person has done. During the second stage, when people start having trouble with communication, doing things, and perceiving the world, the care giver has to deal more with trying to understand what the person is saying, making sure that the care giver repeats things and says things in very brief phrases rather than long sentenced to help the person understand, that people begin to think about practical things like cutting up a person's food if they can't use their knife any longer and making sure that the patient doesn't wander away because face the issues such as getting lost, having trouble driving, using weapons, driving a lawnmower even become more prominent. So the care giver is in a difficult situation often of putting more limits on the activities of the old person and that's a challenge. And then finally in the third three year stage when the physical problems develop, the person needs to make, the care giver needs to maker sure that physical needs can be met. If a person needs help getting out of bed for example, it may take more than one person. It may take thirty minutes or an hour to feed someone who can no longer feed them self. And here's where I think it's really crucial for the care giver to really be able to turn to other people and accept some help with the physical care.

JON MERRIL: Dr. Rabins, how frequently is Alzheimer's misdiagnosed? Are patients coming in that think that they have Alzheimer's disease or care givers that think that a loved one may have Alzheimer's disease but they really don't?



PETER V. RABINS, MD
PRESENTER

Professor of Psychiatry and Behavioral Sciences Johns Hopkins University School of Medicine.

Senior Faculty
The Copper Ridge Institute



JONATHAN MERRIL, MD
MODERATOR

Faculty, The George Washington University Medical Center

Board member, Institute for Advanced Studies in Aging and Geriatric Medicine
CEO, Astute Technology

PETER RABINS: Well that occurs on occasion. So somewhere between two and five percent of people who have the symptoms of dementia have a disease that could be treated like thyroid disease or a brain tumor and there's a long list of things that are potentially treatable even though they are uncommon. Probably the most common cause of treatable memory loss and dementia is still medication toxicity and depression still sometimes gets misidentified as dementia, although in the long run some of those individuals later do develop Alzheimer's disease. So yes I have seen some people misdiagnosed, but often I see the opposite which is a situation in which the family notices something wrong but have no idea if in the area of memory or thinking. And so that I end up seeing the person 'cause there's a lot of frustration or anger in the family. And so that not making the accurate diagnosis Alzheimer's disease or dementia is probably the more common mistake that I see.

JON MERRIL: At what stage of Alzheimer's disease should a care giver consider getting full time help or institutional help in caring for a patient with the disease?

PETER RABINS: Well I think it's different for different situations, different people. And of course it matters what you mean by getting help. I think that help should really begin right at the point where a diagnosis is made so that many people benefit from information, benefit from knowing what courses are available in the community so that the Alzheimer Association or some other community agency can tell them what actually is available. Now later as the disease progresses people might need someone to come in and help or keep an eye on the person or help feed the person. But I think ideally that would begin at the beginning and people would be able to rely on friends, family, and sometimes paid individuals.

JON MERRIL: Can you give us some insights that can help a care giver better manage a patient with Alzheimer's disease?

PETER RABINS: Accepting the fact that the person is ill is important and trying to avoid the trap of feeling that you as a caregiver are the only person who can really manage things. I think that's crucial. It's often true that the care giver is the best person or knows the ill person the best and so can manage things, but I see many care givers who become so overwhelmed and overburdened that it adversely affects their health, their mental well-being, and actually their ability to be a care giver in the long run. So I think accepting that this is a disease and asking for help, using the resources that are available, I think that's a very important step.

JON MERRIL: We've talked about different stages of Alzheimer's disease. Is it important for the care giver to somehow measure the stage that a patient is in? And if that is important, are there tools or things that a care giver should look at to help better assess the stage or is there some other things that they should be looking at to help better communicate with the nurses and doctors that are involved in the care of the patient?

PETER RABINS: I think you can overdue the stage approach. I mean I think it's useful in the broad way of helping people know what's coming, but like all diseases each person's illness is different. So I don't think it's useful to say, oh this is the beginning or the end of this stage, or to worry about which stage the person's in. I do think, first answer your question, how do you best get that information? I think this is one of the reasons that people should be followed by a professional who knows the disease. You know so that even if you just go once a year for a check up that you'll have a professional who can say, "Well these are the new symptoms that I see," or you know, "Have you noticed this?" or you can then ask the clinician, the care giver can ask the clinician, "I'm noticing this. Is that a new problem?" I think that's the best way, in each individual case to have somebody who's a professional help you figure that out; what's new, what isn't new, what's changed, what hasn't changed.

JON MERRIL: There are a lot of different specialties out there including psychiatry, gerontology, neurology, family practice, and so forth as well as different types of help care providers: nurses, doctors, all the different help care providers. Who is the best suited to see a patient with Alzheimer's disease on a regular basis?

PETER RABINS: Well I think it partly depends on what's available in the community you live in. But it's my belief that a good primary care doctor should be able to know enough about this disease to be able to help many families. This is a common illness and so that I think it's the kind of condition like high blood pressure or even typical depression that a primary care physician should know about. However there are lots of situations in which there are particular problems in which there are, for example behavioral or neural psychiatric symptoms that are very difficult to manage. Well that's when I think it's worth seeing a geriatric psychiatrist. I think if the diagnosis is unclear, if it begins in a young person, if there are abnormalities in the neurological examination, a person's weak or stiff on one side or may have had a stroke or has Parkinson's disease, other causes of dementia, then I think they should see a

neurologist for an accurate diagnosis and management. Some communities have geriatric medicine specialists and many of them, like a primary care physician, I think have the skill. So I do think it partly depends on the particular condition and symptoms of the individual patient. And you know some conditions, some communities have either private practitioners who have set up memory centers or have Alzheimer disease research centers where people are available to provide ongoing clinical care. And I think those can be particularly useful to people. I think as far as nurses and social workers and psychologists, many of them have the expertise and special expertise to manage the disease, some don't. And so I think the best thing if someone has a question is to either ask their doctor, "Who in the community is good at this?" or second to ask the Alzheimer Association or local agency on aging if they know of specialists who, again whether it's social workers who might know community resources or do counseling, people who ask those individuals, "Who has expertise in our community to help Alzheimer families?"

JON MERRIL: Do you think that institutions that focus on Alzheimer's disease and dementia offer a higher quality of care and better quality of life for patients that go to those institutions?

PETER RABINS: I wouldn't want to generalize. Again I think that for many patients and many families the primary care doctor has enough knowledge. Then again I think there are lots of situations where a specialist is useful. This is true I think in all of medicine. And so I think if things aren't going well, that's when you need to be seeking out more specialty care. So you know if something happens that seems unexpected or problems develop over time that the primary doctor doesn't seem to be able to advise people on or manage, then I think people should start to ask, "Well you know could we see a specialist and who's available in our community?"

JON MERRIL: Can you comment on the advances the drugs and pharmaceutical companies are making on the treatment of Alzheimer's disease as well as different other types of therapies such as psychological interventions or maybe even mental exercises can have in changing the course of Alzheimer's disease?

PETER RABINS: Treatments are improving both in the pharmacologic and in the non-pharmacologic realm. So to start with the medication, the three drugs that are available today are modestly helpful for treating early and middle stage Alzheimer's disease. And those drugs and I'll use the brand names: Aricept, Exelon, and Razadyne. And then memantine has been approved for people in the middle and third stage of the disease and I think it adds a modest benefit to those other medications. There are a large number, maybe more than sixty drugs that are at some point in testing close to human testing now or in human testing that have the possibility of being more effective, maybe actually changing the biology of the disease. I don't think right now we know that any of those are really going to make a difference, but I think there's lots of hope. So I think on the medication side, I think there are a lot of exciting things happening. I think we're continuing to learn the importance of activity and stimulation and particularly to match the amount of stimulation and the type of stimulation and activity to the person's abilities, what they can, the ill person, what they can still do. And kind of to what they were interested in doing before they became ill. And so I think there's a whole gamut of things that people are learning in that realm as well. And also I think we're finally kind of learning how to build better environments to meet people's needs who have dementia and Alzheimer's.

JON MERRIL: And what do you mean by "environments?"

PETER RABINS: Well, I think we're learning that too much noise isn't good, that allowing people to wander and move freely, that for many people that's a real benefit. I think we're learning that if you can build in stimulation and activities into the environment where the person is, whether it's at home or in a long term care facility or assisted living. But actually having the activities right there in the facility ongoing through the day, that can help. And the other important aspect of environment is the people that work there or live there and do they know how to approach the memory and cognitively impaired person? Can they be supportive? Do they know to repeat things several times, to say things in a simple way, to hug people when it's appropriate, to give them encouragement when it's appropriate, to back off when it's appropriate? That's an important part of the environment.

JON MERRIL: What do you think about the concept of memory aids? Could a patient with Alzheimer's disease take notes and note cards and put them in his or her pocket to help remind them of things that they need to do or remember or could they even use electronic aids like a palm pilot or a pocket PC to remind them of these things?

PETER RABINS: So there are some patients at the beginning who are helped by having a little notebook in their pocket where they can write things down, write what appointments are coming up, what their doing. And they, and people get used to checking that.

And for many people that's very reassuring. You know as the disease progresses people are less able to do that. I think if somebody's used a palm pilot, a PDA, or whatever in the past that might help them. It's hard for people to learn new things like that that they've never done before. But I think there will be technologies coming on that can remind people and encourage them and so I'm really looking forward to more and better technologies coming along. You know one of the rules that I try to follow is that there aren't any rules. And so I think a lot of this is trial and error. And so I think it's always better to try something and fail then to not try it at all. And sometimes I'm surprised what helps a person remember and other times I'm sure that something will make a difference in a positive way and we try it three or four times and not only does it not help but it makes the person more frustrated and then we have to figure out that we need to back off. So I think it's worth trying reminders of all sorts and encouragement and showing people how to do things. People can learn to do new things. And so we do want to try to teach them new things as well.

JON MERRIL: Is there a way to predict the course of the disease, some method for figuring out how rapid or how slow mental decline will occur in a particular patient?

PETER RABINS: Well the best guide is what's happened in the past. So if a person's had a very slowly progressive condition, it's likely to progress slowly. If it's been more rapidly progressive, it's likely to change more rapidly. But having sort of said that, there's a lot of variability and some people all of the sudden stop progressing and don't change very much for a year or two and then all of the sudden they'll get worse again. So I think there are rough guides and that's why I like to break things into stages 'cause I think it gives some guidance about the future, but I that's often as wrong as it is correct.

JON MERRIL: There's been a lot of information in the press recently about video games that are being used to help increase memo acuity. Do you see a role for these types of games and programs to help people retain their memory?

PETER RABINS: Well I, you know I think most of that that I know of has been in preventing the disease. I think that my understanding of the scientific literature on that is that you can help people improve their performance on a particular game or activity. But that it doesn't really seem to generalize to other thinking functions. So I think right now if somebody enjoys that sort of thing, they should do it. But I think if it's frustrating, then we shouldn't have people do that and I don't think we should expect right now that that will really alter the disease progression itself.

JON MERRIL: And your background is in psychiatry. Does that give you a different perspective? There's obvious richness with each medical specialty as you look at a disease state. How do you, what do you think the unique qualities of your background in psychiatry, when you observe a patient are you looking at things a little bit different than a neurologist would or a general practitioner? If a care giver is listening to this presentation for example, what could they hope to glean additionally from someone with a psychiatry background versus another background?

PETER RABINS: Let me start maybe with a different questioning point which is I think first that a lot of the knowledge base about all the dementias and Alzheimer's disease are shared by medical professionals, physicians, psychologists, etc. So whether it's a neurologist, a psychiatrist, a geriatrician, or primary care doctor I think the basic facts of the disease, recognizing the symptoms etc., I would hope would be in the armamentarium of all those individuals. I think what specialists bring is a knowledge about a particular aspect of the disease. So that neuropsychiatrists and geriatric psychiatrists have particular training in what are called the neuropsychiatric or behavioral symptoms. So problems like hallucinations, delusions, agitations, apathy, there's a whole range of symptoms that people call behavioral or psychiatric or psychological. I think that's the particular expertise that a geriatric psychiatrist and neuropsychiatrist would have. Neurologists have you know really in depth training in rare brain diseases, in eliciting the symptoms of the physical neurological examination. And so particularly for the less common conditions or diseases like Parkinson's disease or multiple sclerosis or a whole range of illnesses that have specific treatments like Parkinson's disease, that's where a neurologist might be particularly useful and have a particular knowledge base. Many older people who have dementia have many complicated medical situations and I think this is where a geriatrician or geriatric medicine specialist can be useful because when people need to be on lots of medications and they don't, not only have dementia but have heart failure, or arthritis and kidney disease, etc. having one person who can manage all the medications and all the tests and all the medical problems that come up, I think it's an expertise that geriatricians can bring to the situation. The other aspect that specifically relates to care givers is taking care of someone with this illness can be emotionally difficult as well as physically difficult. And I think different physicians and non-physicians have training and expertise in also helping care givers adjust their own psychological needs. And so that's the sort of thing that sometimes psychiatrists are more interested or psychologists, social workers. But I know many neurologists and primary care doctors who are also extremely supportive and helpful to family members.

JON MERRIL: What is the impact of care giving on health? In other words, how does giving care to a patient that has Alzheimer's disease influence the care giver's health? Are there challenges that we need to be aware of?

PETER RABINS: I'm amazed at how well many care givers do. Being a care giver is very difficult 'cause you're balancing physical concerns, financial concerns, worries about the rest of the family, worries about your own health, etc. And the majority of care givers actually are able to get resources and help on their own. So the majority of care givers actually don't need specific professional help or if they do they can get it specifically for the problem that they need. However care givers are as a group taking very high stress and distress levels. Probably triple the rate in the population that isn't a care giver. And so I think there is a very important role that professionals play in providing emotional support for the care giver and giving specific practical advice and making sure that people are paying attention to the financial issues, the legal issues, the ethical issues, and the kinds of concerns that have come up. And one of the reasons that I emphasize the important role of primary care doctors is that there are so many different kinds of care givers, not just for dementia but for many chronic illnesses that the primary care doctor is a good place to start and they can often, if a care giver needs more emotional support, they can direct them to a social service agency, a social worker, a nurse counselor, a psychologist, etc. that can provide that kind of help. So there's a big need but I think it's important to keep in mind that a lot of care givers do well without particular help.

JON MERRIL: Dr. Rabins, you shared some fascinating insights into Alzheimer's disease from the perspective of the care giver. Are there any additional comments or suggestions that you'd like to give our audience?

PETER RABINS: The point that I'd like to end on is that while care giving is very difficult and while the dementias are devastating illnesses, that there is a positive side to care giving. I think it's extraordinary, the sacrifices that care givers willing and lovingly provide and I think it says a lot to the human experience for the role that families play in our lives, that religion, social support plays in people's lives. And so while there are burdens that come with care giving there are positive things as well. And I think we should have a balanced view that it's a two edged sword.

JON MERRIL: Well thank you so much Dr. Rabins for sharing your valuable time with us and we really appreciate your insights and we look forward to talking to you again in the near future.

PETER RABINS: Thanks, Jon. Bye bye.

JON MERRIL: This concludes our program on care giving and psychological issues featuring Dr. Peter Rabins, Professor of Psychiatry and Behavior Sciences at the Johns Hopkins University School of Medicine and Senior Faculty at the Copper Ridge Institute. Thanks for joining us and stay tuned for the next podcast on Alzcast.org.



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