Reducing Behavioral and Psychological Symptoms of Dementia: Family Caregivers

Informed Consent Document

Principal Investigator: Liron Sinvani, MD
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Northwell Health
Campus: North Shore University Hospital/Long Island Jewish Medical Center
Verbal Consent for Participation in a Research Study: Legally Authorized Representative and Family Caregiver is same person
Study Title: Reducing Behavioral and Psychological Symptoms of Dementia (BPSD) for Acutely-Ill Persons with Alzheimer's Disease and Related Dementias via Patient Engagement Specialists
Principal Investigator: Liron Sinvani, MD
Sponsor: National Institute of Aging

This research study is being led by Dr. Liron Sinvani at Northwell Health. Participation is completely voluntary and you may choose not to take part or stop at any time. This decision will have no effect on your loved one's medical care and will not result in any penalty or loss of benefits for your loved one**.** You should ask questions before you decide if you want to participate. You can also ask questions at any time during the study. A copy of the consent form will be sent to you.

The purpose of this research study is to test a new model of care to improve the experience and outcomes of hospitalization for both patients with dementia and their caregivers. Specifically, we are testing a new model of care that is designed to reduce behavioral and psychological symptoms of dementia (BPSD) and better prepare hospital caregivers to prevent and manage BPSD. You are being asked to participate in this study because you are the caregiver for someone who is 65 years or older, has dementia, and is hospitalized.

After agreeing to participate in the study, your family member's behavioral symptoms that are related to their dementia will be recorded by reviewing medical records and through discussion with the staff. Within 48 hours of discharge, a member of the research team will call you to conduct an interview to discuss the caregiver satisfaction with the care provided during hospitalization.

The patient will not receive and compensation. You will be paid for your time at two time points: $20 upon completion of the enrollment surveys and $10 upon completion of the discharge survey, for a possible maximum payment of $30. If you join the study you may withdraw at any time without prejudice to your loved one's future care at Northwell Health. If you withdraw from this study or if you are withdrawn from the study, any data already collected will continue to be used. However, no new data will be collected.

We will only collect information that is needed for the research. If you consent to the study you are giving us permission to collect, use and share your loved one's health information. This permission is called authorization.

As this study involves the use of your loved one's identifiable, personal information, there is also a chance that a loss of confidentiality will occur; however, the researchers have procedures in place to lessen the possibility of this happening. Additionally, it is possible that topics may come up in the interview that might upset you. Some of these questions may seem very personal or embarrassing. You do not have to answer any questions you do not want. There are no other anticipated risks from taking part in the study. The possible benefits you may experience from the procedures described in this study include improved care and improvement of behaviors that are common for persons with dementia during hospitalization. The information we learn may also help patients with dementia in the future.

Do you have any questions about our study?

At this time, you have been told the risks and benefits of our study and had the opportunity to ask questions. If you have any questions once we begin the interview, I will be happy to answer them. Your decision to join this study is voluntary and you have been informed that you can withdraw from the study at any time without penalty. By agreeing to participate, you are not giving up any of your legal rights.

As the Legally Authorized Representative, do you give consent for _____ (patient name) to participate in this study?

Do you give consent for yourself to participate in this study as the Family Caregiver?