

# Effects on quality of life and family caregiving experiences by the Namaste Care Family program for advanced dementia

<https://neurodegenerationresearch.eu/survey/effects-on-quality-of-life-and-family-caregiving-experiences-by-the-namaste-care-family-program-for-advanced-dementia/>

## Principal Investigators

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Netherlands

## Title of project or programme

Effects on quality of life and family caregiving experiences by the Namaste Care Family program for advanced dementia

## Source of funding information

ZonMw

## Total sum awarded (Euro)

€ 461,702

## Start date of award

01/12/2014

## Total duration of award in years

4.0

## The project/programme is most relevant to:

Alzheimer's disease & other dementias

## Keywords

### Research Abstract

Quality of life of people with advanced dementia in the Netherlands can be improved. People may be isolated as they cannot participate anymore in the activities that are offered. Some

present challenging behaviors, and families may be frustrated with limited contact with their loved ones.

A US program called Namaste Care aims to increase quality of life and comfort specifically for these people. It incorporates person-centered and palliative care approaches and includes end-of-life care. Loving touch, presence of others, and engaging people in meaningful activities, such as gentle personal grooming, are central. Evidence accumulates that the program successfully changed the lives of people and their families in US, UK, and Australian nursing homes. In particular, it improved behavior, reduced use of psychotropic medications and did not increase health care costs.

With the committed support of the developers, experts, and an end-user panel with families and volunteers, we propose to modify the program to sustainably fit it into the Dutch health care landscape. The adapted Namaste Care Family program will emphasize family and volunteer involvement, and end-of-life care.

In 16 nursing homes, a cluster-randomized controlled trial will assess if the Dutch Namaste Care Family program improves outcomes in a cost-effective manner. The primary outcomes are patients' quality of life and families' positive caregiving experiences. Secondary family outcomes are caregiver burden, (pre)grief, and perceptions of caregiving role.

To assess effects and the most effective components (elements) of the program, we will perform longitudinal mediation Structural Equation Modeling (SEM) analyses.

An economic evaluation will relate the difference in societal costs to the difference in quality of life and positive caregiving experiences attributed to Namaste Care Family. Both a cost-effectiveness and a cost-utility analysis will be performed.

Regarding sustainability, any resources such as supplies lists and an instructional video will be translated or developed, and improved for an accessible toolkit for further implementation. We will train "champion" families and volunteers to become trainers themselves.

## **Lay Summary**

**Further information available at:**

### **Types:**

Investments > €500k

### **Member States:**

Netherlands

### **Diseases:**

Alzheimer's disease & other dementias

### **Years:**

2016

### **Database Categories:**

N/A

### **Database Tags:**

N/A