

Thinking ahead: supporting family caregivers of nursing home residents with dementia in advance care planning Bayelaar-von Oerthel. L.

Citation

Bavelaar-von Oerthel, L. (2023, February 28). *Thinking ahead: supporting family caregivers of nursing home residents with dementia in advance care planning*. Retrieved from https://hdl.handle.net/1887/3566618

Version: Publisher's Version

Licence agreement concerning inclusion of doctoral

License: thesis in the Institutional Repository of the University

of Leiden

Downloaded from: https://hdl.handle.net/1887/3566618

Note: To cite this publication please use the final published version (if applicable).

Thinking Ahead

Supporting family caregivers of nursing home residents with dementia in advance care planning

Laura Bavelaar-von Oerthel

Academic network for research in elderly care

The studies in this thesis took place in the University Network for the Care Sector South Holland (UNC-ZH). In this network, the Leiden University Medical Center (LUMC) collaborates structurally with 12 elderly care organisations in South Holland (Marente, Pieter van Foreest, Florence, Topaz, Argos Zorggroep, Saffier, Laurens, Zonnehuisgroep Vlaardingen, Woonzorgcentra Haaglanden, Aafie, ActiVite, Haagse Wijk- en Woonzorg).

Caregivers, policy makers, researchers, students, residents and relatives work together to improve the quality of care and quality of life for vulnerable older people. The UNC-ZH is a regional platform, inspirator and learning network for innovation in long-term care. Research, education and training, and practice are closely related.

Thinking Ahead - Supporting family caregivers of nursing home residents with dementia in advance care planning

© Laura Bavelaar-von Oerthel, 2023, Leiden, The Netherlands

All rights reserved. No part of this book may be reproduced in any form by print, photo print, microfilm, or any other means without permission from the author.

Printing by ProefschriftMaken | www.proefschriftmaken.nl ISBN 978-94-6469-157-3

The studies presented in this thesis were funded by the Netherlands Organisation for Health Research and Development (ZonMw) program Memorabel grant number 733051084 under the aegis of the EU Joint Programme - Neurodegenerative Disease Research (JPND) - www.jpnd.eu. Financial support for printing of this thesis was kindly provided by the Department of Public Health and Primary Care of Leiden University Medical Center, the Netherlands.

Thinking Ahead

Supporting family caregivers of nursing home residents with dementia in advance care planning

Proefschrift

ter verkrijging van
de graad van doctor aan de Universiteit Leiden,
op gezag van rector magnificus prof. dr. ir. H. Bijl,
volgens besluit van het college voor promoties
te verdedigen op dinsdag 28 februari 2023
klokke 10.00 uur

door

Laura Bavelaar-von Oerthel
geboren te Leiderdorp
in 1993

Promotor

Prof. dr. W.P. Achterberg

Copromotoren

Dr. ir. J.T. van der Steen

Dr. M. Visser

Promotiecommissie

Prof. dr. Y.M. van der Linden

Prof. dr. L. van den Block, Vrije Universiteit, Brussel, België

Dr. M.A.A. Caljouw

Dr. J.M.M. Meijers, Maastricht University, Maastricht

Table of Contents

| Chapter 1 | General introduction | 8 |
|-----------|--|-----|
| | Part 1. Palliative dementia care: avenues for improvement | |
| Chapter 2 | Physicians' perceived barriers and proposed solutions for high- quality palliative care in dementia in the Netherlands: Qualitative analysis of survey data | 20 |
| Chapter 3 | Interventions to support family caregivers of people with advanced dementia at the end of life in nursing homes: A mixed-methods systematic review | 50 |
| Chapter 4 | Change in advance care plans of nursing home residents with dementia and pneumonia: secondary analysis of RCT data | 106 |
| | Part 2. The mySupport study intervention | |
| Chapter 5 | Guidance for family about comfort care in dementia: a comparison of an educational booklet adopted in six jurisdictions over a 15 year timespan | 126 |
| Chapter 6 | Developing country-specific questions about end-of-life care planning for nursing home residents with advanced dementia using the nominal group technique with family caregivers | 154 |
| Chapter 7 | Changing and shifting tasks from physicians to nurses in advance care planning with family caregivers of nursing home residents with dementia: mySupport case study | 178 |
| Chapter 8 | General discussion | 202 |
| Chapter 9 | Summary | 220 |
| | Nederlandse samenvatting | 225 |
| | List of publications | 231 |
| | Portfolio | 233 |
| | Curriculum Vitae | 235 |
| | Dankwoord | 236 |