STAYING IN LIFE

PAVING THE WAY TO DEMENTIA-FRIENDLY COMMUNITIES
We are constantly growing older, and there are an increasing number of elderly people living with dementia who are merely being ›taken care of‹. There is no question that we need alternatives to the established procedures.

What can we do to create spaces where we can stay in life – rather than just staying alive? How can we turn the individual environments of people with and without dementia into ›places of human warmth‹?

In Germany, initiatives attempting to answer these questions are on the rise: Committed individuals from politics, art, churches, social and volunteer work etc. are creatively working towards dementia-friendly communities. In this book, three authors, intimately familiar with the topic, explore initial movements, obstacles, and first approaches.

Verena Rothe (MA), is sociologist and leader of the project »Menschen mit Demenz in der Kommune« and managing director of Aktion Demenz e.V., Gießen, Germany.

Gabriele Kreutzner (Dr.), cultural and media scientist, is actively engaged in projects related to dementia and is co-chair of Aktion Demenz e.V. She lives in Stuttgart, Germany.

Reimer Gronemeyer (Prof. Dr. Dr.), theologist and sociologist, is researcher at Gießen University. He published on dementia and is chairman of Aktion Demenz e.V.

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Opening remarks by the Robert Bosch Foundation

Dementia as a social issue has moved from being a niche topic to becoming part of German public discourse. Finally! Ten years ago, nobody could have imagined books about dementia on bestseller lists or cinemas screening films on dementia that feature famous casts. Dementia sells – this at least means that things have changed. And what we had feared has not come true; dementia has not become a prop of apocalyptic images. Instead, in ageing Germany – as well as in its neighbouring countries –, people are tackling the important questions: How do we encounter those who are confused? What can we do? How can politics, care providers and civil society meet the challenge of dementia?

The Robert Bosch Foundation started talking about dementia more than 10 years ago, when it was only “discussed” by experts, and considered a niche topic even in those circles. The foundation laid a foundation, brought academic research and practice together, and started a two-year networking initiative Gemeinsam für ein besseres Leben mit Demenz (‘Working together for a better life with dementia’). Back then, our goals were: connecting the efficacy of established best practices with the breadth of experiences made; finding gaps in existing care structures and trying out new approaches; strengthening chances for success and sustainability of activities through co-operation; and founding a network as the foundation for an action programme. The exchanges between medicine and sociology, care and social work, universities and civil society that emerged as a result gave rise to impulses and inspirations for a different approach to dementia. Experiences from neighbouring countries as well as a week-long visit to the Dementia Services Development Centre in Stirling in Scotland also contributed to the project. There, Mary Marshall pioneered many valuable approaches in accompanying people living with dementia.

How can we support people with dementia early on? How can we preserve their abilities for as long as possible? How can we support them in co-operation with and between experts and friends and families? How can we make sure that people with dementia receive the right and sufficient nutrition? Which ethical and legal questions and connections are relevant in
relation to dementia? These are the questions with which about seventy experts grappled in networking workshops over the course of two years. They investigated where there was need for action and where there were possible solutions. But this was not the end of the journey for everyone involved.

The initiative became the starting point for a new beginning, whose effects are clearly noticeable today. The association *Aktion Demenz – Working together for a better life with dementia* emerged from this networking initiative based on prompts from the *Robert Bosch Foundation*. From the beginning, the board was comprised of individuals from the academy as well as civil society that were willing to work towards giving the topic of dementia more visibility in Germany and paving new ways in dealing with the issues raised by dementia. Among many other topics, a core emphasis of *Aktion Demenz* has been making clear that dementia is not only the responsibility of physicians and care workers, but that a better life with dementia needs to be based on the links between many different factors, especially in the daily lives and interactions of people in their own communities. With this goal in mind, *Aktion Demenz* focused on the area of ‘dementia and the community’. They suggested a funding programme to the *Robert Bosch Foundation* that was intended to help get initiatives started in communities and on their way to changing the relationship between society and dementia. Soon, the term ‘dementia-friendly community’ became established as a keyword that has arrived in many German-speaking communities. There is little question that this is primarily due to the funding programme set up by the *Robert Bosch Foundation* and realised by *Aktion Demenz*. Over the course of three funding cycles, dementia was established as a topic near the top of the agenda in many German municipalities, cities, towns, and other communities. It funded almost eighty projects, whose ideas and approaches invite others to copy, continue and develop further what they have begun. The emphasis was not on new professional care structures but rather on involving civil society actors in the communities. The goal of creating ‘dementia-friendly communities’ has proved contagious. For example, an Austrian ‘Aktion Demenz’ was founded in Vorarlberg in Austria, and exchanges between the
Robert Bosch Foundation and the Belgian King Baudouin Foundation led to the creation of the European Foundations’ Initiative on Dementia – a coalition currently composed of seven foundations that aim to foster networks between people, organisations and projects across Europe that work towards ‘Living well with dementia in the community’.

The Robert Bosch Foundation provided further emphases through education and training opportunities, including short guest stays in other countries for executive staff in health care institutions and a postgraduate programme on dementia. Currently, the foundation supports emergency hospitals in finding ways of treating patients with dementia gently, in order to alleviate the potential impact of vulnerable moments such as hospital stays resulting from general medical problems or surgeries.

We are happy that the initiatives of the Robert Bosch Foundation and Aktion Demenz have been taken up by the Allianz für Menschen mit Demenz (‘Alliance for people with dementia’), founded and funded by the German government. Through it, the credo of Aktion Demenz – ‘Working together for a better life with dementia’ – has been put into a larger context.

We hope that as dementia has left its position as a niche topic in the mass media, the idea of ‘dementia-friendly communities’ will likewise grow beyond the individual, exemplary local initiatives. We hope that in the future, people with dementia will be able to live good everyday lives in our communities, that they will be cared for, and that they will be able to actively participate in their own lives.

Dr Bernadette Klapper
Robert Bosch Foundation, July 2016
It may seem presumptuous to add yet another book on dementia to the many that already exist. However, here we are doing so, and with good reason. With this book, we look back at a process whose vehemence surprised us. In 2004, the Robert Bosch Foundation got the ball rolling with the initiative workshop ‘Working together for a better life with dementia’. It had the foresight, sensitivity and courage to consider the social side of dementia. The question was: How are we going to address the fact that more and more people live with dementia, if not with more engagement by civil society?

We at Aktion Demenz caught that ball that had been passed to us, and since 2006, we have worked towards making ‘dementia and the community’ a subject matter for discussion in communities and have sought to nurture a willingness to act on these discussions. This book is intended to showcase the results of the efforts made by initiatives across the country, and to connect them to their various practical and theoretical contexts and implications. The dementia-friendly community is like a pebble that, once thrown into the water, causes further ripples. In other words, we shouted ‘dementia-friendly community’, and the call reverberated with innumerable, amplified echoes. Each initiative developed its own way of doing things, and together, they form a bouquet of diverse possibilities that this book seeks to relate.

The book is not a seamless surface, however. After all, three different authors were involved in its writing. But we hope that taken together, the three different pitches presented herein will provide a harmonious chord.

It was at very different points in our lives that we encountered the topic of ageing and dementia. Equipped with different perspectives, experiences, and mental as well as practical tools, we discussed and started the idea of dementia-friendly communities with our work in the Aktion Demenz association. Accompanying a larger number of projects and initiatives across Germany that all sought to improve the lives of people living with dementia – as well as their friends and families – in their local communities prompted and enabled us to engage with the differences between theory and practice, and to make them tangible for continuing to develop ways of thinking and acting.
We are overjoyed that dementia-friendly communities has become a key term that has entered discussion in many places and at many levels. Inspired by this vision, people’s efforts have led to the founding of new initiatives; and many a councillor, member of a provincial government or mayor could not resist the contagious power of these ideas. The wave of dementia-friendly communities has also reached the Lokale Allianzen für Menschen mit Demenz (‘Local alliances for people with dementia’), which are funded by the German government. It remains to be seen whether the efforts of members of our society aimed at making it a warmer and kinder place will retain their central position. Fostering the growth of a grassroots movement for people living with dementia is a core tenet of Aktion Demenz, and it must remain so in the service of people living with dementia as well as their friends and families. The dementia-friendly community harbours the possibility of re-imagining and re-building a society of isolated individuals in which only paid service providers provide the help needed by individuals. Understood this way, dementia-friendly communities are about inventing a new way of living with each other rather than just next to each other.

Verena Rothe, Gabriele Kreutzner, Reimer Gronemeyer
Gießen, July 2016

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