

Welcome to this podcast from Leeds Church Institute, recorded at the launch of Journeying Together: Accompanying People Living with Dementia, a new book by Joseph Courtis and Peter Matthews. The launch was held in late June 2023 and was hosted by LCI and Growing Old Gracefully. This is the first of three podcasts and is the introduction to the book launch given by Revd Dr Joe Cortis, who is a former senior lecturer and Associate Director of Education for Postgraduate Courses for the School of Health Care at the University of Leeds. He is the coordinator of Caritas Leeds and is one of the co-authors of the book.

First of all, good afternoon and thank you for sparing the time to attend this launch. I would like to start by thanking Carol, who is the chair of the Growing Old Gracefully, and Dr Helen Reid of Leeds Church Institute for organising this event. This is very much appreciated.

This launch has also prompted me to read the book through once more. I also want to welcome Pia, the other co-author and Sister Janet, who is at the back who works for Redemptorist Publications, who was the editor of the book. I personally feel very humbled that together with the contributions of other co-authors, Pia Mathias and Belinda Moe, who is here, and Sister Bernadette, all members of the Caritas Leeds Dementia Group, and Lucy, my daughter, this book saw the light of day in a printed version in February. Dr. Pia Matthews is a senior lecturer at Saint Mary's University in Twickenham and Director of Studies at Allen Hall Seminary in Chelsea. In 2015, Pope Francis appointed Pia, an expert to the 14th Ordinary General Assembly Synod of Bishops.

The title of this book is Journeying Together: Accompanying People Living with Dementia. I suggest that there are three key words which provide the essence of this book. We are all on our own individual journey, but whilst it is unique to each one of us, we need to be accompanied and indeed accompanying others. The other key word is living. The word dementia is particularly important in the context of this book, so the word living is particularly important. This word dementia generally frightens people and triggers a lot of perhaps negative emotions. However, our message is that with support, understanding and love, one can live well with dementia.

This, of course, does not negate against the challenges and sufferings along the journey of accompanying somebody who is living with dementia because these are the realities of those concerned. One of the key challenges is that of the stigma about dementia. Once being given the label of dementia, people tend to isolate themselves, stay at home, withdraw from previous engagements. But the question is how do others respond to this challenge? Our response, I would suggest, need not be purely driven by a sense of charity, but that we are all of the same origin created in the image of God and all have the same destiny.

The person living with dementia is actually giving a lot to other people. This book is not a publication about misery and tragedy, but a book that says that we are all able to give something in life. You can bring something to the table and play a part in the community. So this book offers both, takes a practical and an academic approach as well. I would now like to offer an overview of this book without giving too much away, because of course you've got to read it well to buy it first and then read it.

Okay, so we invited contributions from people with direct experience in caring for or ministering to people living with dementia and their families. So capturing their story was fundamentally important to us. If as individuals, parish groups, etcetera want to accompany someone, then we need to listen to their experience. What we heard were different perspectives, which raised challenging questions for us, but I would suggest also kept us grounded in the realities of living fully with dementia. Now,

following the capturing of their stories, we also worked with these individuals to help them reflect on the following. Looking back at your experiences, what advice did you need? What advice would you give yourself? What resources did you need and what and what did the person living with dementia need? This suggests this approach was important to us because this book is not only about listening to their voices, but we aim to learn from their experiences so that this book can offer practical advice on how to effectively accompany somebody. This includes, of course, coping with the diagnosis, the need for effective communication, channels of support, especially for family members, communication with clergy, etcetera. Now, one specific issue addressed in this book is the concept of living well with dementia as a contributor towards an effective accompanying journey. Living well with dementia also means taking into account of some of some of the more challenging realities. But in naming these challenges, we do not take away from living well. Rather, we hope that we can give strategies for coping conscious that human beings are generally very creative in finding ways to live well. Specifically in Chapter three, we explore strategies for living well with dementia and what might work to create dementia friendly communities.

Earlier I stated that we have not shied away from challenging issues. Hence, chapter four continues the theme of accompanying people living with dementia and their families through dying, death and bereavement. Another thread of this book is spirituality. We believe that spirituality is essential to every person, although it is often invisible. It goes beyond the tangible aspects of daily life to promote a deeper understanding, a deeper awareness and understanding of the perceived meaning of life. All human beings are spiritual. Whether or not they belong to a particular religious tradition themselves or consider themselves indeed to be religious. Sadly, in our increasing secular society, it is often the case that this aspect of a truly holistic, professional and lay care setting is often neglected. This is perhaps even more the case in dementia. So in this book, we offer a framework for assessing spiritual needs and how to act on what has been discovered through the assessment. This, I would suggest, is particularly useful for professional carers, clergy and lay faithful ministering to the sick and indeed those living with other disabilities. I think there is a lot of transferability here. One of the key aspects of caring for someone living with dementia is the issue of decision making. Here I'm very grateful to my daughter Lucy, who is a solicitor who contributed a chapter titled Making the Legislation Work for You. Indeed, this has also prompted us to organise our own LPAs and wills. So that's in the book somewhere.

This chapter on legal issues addressed in detail the concept of advance care planning, the assessment of mental capacity, because this issue is a very thorny issue. Mental capacity is situational, not across the board. Lasting power of attorney for both health and welfare and property and financial affairs. We also offer a chapter of, I think, specific relevance to the clergy in regards to the administration of the sacraments of the church. Now, of course, whilst this is based on Catholic canon law, the theological insights that we bring to the table can be a source of fruitful dialogue in building up dementia friendly communities. We also share the experience of the work carried out by Caritas Leeds, aiming for the Catholic Diocese of Leeds to be more dementia friendly. A number of resources have been developed targeting the lay faithful carers, clergy and religious. Now the driver of this book and what we have learned along the way fit neatly into the identified method in Catholic social teaching of See Judge Act, which some of you may well be familiar with. And as Justin Welby, the Anglican Archbishop of Canterbury, says in his book Reimagining Britain, the values and aims of Catholic social teaching can be a source of fruitful reflection for all Christians. Hence, Chapter nine offers a framework for action. Now, in some chapters, we offer an opportunity for a personal response on what the reader has just read. And also, please note that each of the nine chapters invites the reader to reflect by drawing their own response to some specific questions.

I hope that this book contributes to the conversation to enable people living with dementia to live well and fully, individually and in community. By breaking down the barriers through our dementia voices, we hope that people will feel more able to share their diagnoses, in the knowledge and indeed confidence that they will be supported and heard, that they will not only be welcomed in dementia friendly churches and communities, but be encouraged to participate and share their individual and unique contributions to those communities. We hope that our communities will develop beyond adjusting and creating accessibility to growing genuinely inclusive rather than exclusive communities. We hope that we have provided voices at the service of the church, especially during this current worldwide synodal initiatives. We trust that our communities can identify unmet needs, help in the provision of resources, and not only listen further to people's voices, but also act on these voices. We trust that sharing our practice and sharing both the realities of the pain and joy in people's journeys will contribute to a way forward that is inspired by hope, which is the Christian message.

*Thank you for listening to this podcast from Leeds Church Institute. Do check out the others in the series. The book *Journeying Together* is published by Redemptorist Publications and is available for £11.95 from www.rpbooks.co.uk. This podcast was edited by Matt Collins of online events and the music was by Audio Coffee from Pixabay.*