

Welcome to this podcast from the Leeds Church Institute, recorded at the launch of Journeying Together: Accompanying People Living With Dementia, a new book by Joseph Cortis and Pia Matthews. The launch was held in late June 2023 and was hosted by LCI and Growing Old Gracefully. This is the second of three podcasts. And in this one, Sir John Battle MP responds to the book. Sir John was MP for Leeds West from 1987 to 2010, and former Minister of State for Foreign and Commonwealth Affairs, and Minister of State for Trade and Industry.

Can I say to start with I think we should say thank you to Joe, Pia, and the publishers for this volume. And thank you for giving me an early sight of it, and the privilege of being able to read it in advance. And I want to say in a way, it's not a medical textbook on gerontology and I think Joe spoke to his experience in health, but I think it's also a deeply spiritual and theological book.

I've read it a couple of times and gone back to it, and I want to suggest I've no experience yet, as far as I know myself of dementia, who knows of any of us, nor have I within my family. But I want to suggest that this book is more than just a handbook for dementia carers and people living with dementia. It's got a wider life guide for all of us now, and the themes that I took from it were threefold, a little bit like Joe's words. And the themes were... Our identity as human beings, as a person, our identity is social. The second theme is that notion of active living with, positive living in the present. And the third theme that I picked up from it, was connection as hope. And I thought that those themes are deeply, coming from Joe in his speech, from a deeply spiritual theological tradition that's embedded in the book that you don't often get. So I see this book as a kind of practical workbook, not something to read or the summary of a person's research that's left on a shelf, but something that all of us should read for everyone and that we can work with the content and the different pages of it.

And I was particularly, in other words, excited, I suppose, by the title: Journeying Together and it reminded me of a passage of Pope Francis early in his papacy in the Church of Mercy when he suggested that the whole point of our life, as it were, is walking with other people. He said this: "What could be more beautiful than walking with people? Sometimes in front, sometimes behind, sometimes in the middle, in front in order to guide the community. In the middle in order to encourage and support, and at the back in order to keep it united so that no one lags too, too far behind to keep them united." He said, "It's important to walk in unity without running ahead, without nostalgia for the past. And while you walk, you talk, you get to know one another, you tell one another about yourself, you grow as a family."

So let's ask ourselves, how do we walk? How does our community walk, our diocese walk, do we walk together? And what are we doing to make sure we walk truly in unity? And it's that motion in walking, I just wish in my own experience that I'd had this book when my father died who was struck down with a stroke and spent two years unable to speak. And it was that challenge of going to visit him and learning to communicate just with gentle touch and your eyes, and sometimes when he was just asleep, being there all the way over to Wigan and coming back again while he slept. And the challenges of that, I felt it resonated through this book. The challenge of our brother in law, who had a terrible stroke, caring for him at home. The challenges that caring throws up for both the person and the carer. I just wish I'd had the book before, because it's well overdue. But it could serve, even I remember taking Holy Communion in our parish to a care home. Even the hints here of how that can be handled, and of course people in those circumstances 80% may well have dementia.

So caring for the person and taking you to the heart of the experience for you, if you just pick up the book and start to read it, the first 40 pages are those stories, those narratives. Of those people, Maggie, Andrea, Mike, Maureen and Rhoda. So powerful, that you immediately make personal connections with your own circumstances and wider experience. That first 40 pages of experience. But what echoes through the whole book is this sentence, and Carol reinforced it. Each person living with dementia is unique. In dementia, there is no one size fits all. So the message, all the way through, is you have to be attentive to the person, always be aware, and treat them, regard them as someone who can contribute.

And it's that person centered, person focused approach that's really at the heart of the dignity of the person. Central, yes, to Catholic teaching. And perhaps, as we ought to emphasize, to all human social relationships. And the book's packed with practical advice, whether it's the legal advice, I could well have done with the lasting power of attorney, rules of change, how do you handle attorney, how do you handle the Mental Capacity Act. There was a sentence that echoed to me from, the Catholic bishops have just put out a document called Love the Stranger. And it is about asylum seekers and refugees and buried in there was a very strong statement which said, love the stranger. Each person has a face and a name and an individual story and must not be reduced to numbers and statistics. And I thought that was a very powerful phrase that echoed through this book all the way. I was starting to meet people who with dementia and caring for people. But then it was that positive as, as Joe... Spelt out. That active living with. That was the most encouraging and positive advice to be found in the whole book. And yes, there were the references. If you read the book, you'll see great hints of places to go, memory boxes, the SCARS framework. You will probably know it as well, well as I. Stressing good communications. The need to work at communicating, and I just felt that applies to everybody. We're all bad at communicating. There was a lovely sentence. 2Good communications requires attentiveness, thoughtfulness, and planning, especially if the conversation may be difficult for the individual and for the would be communicator." We could put that on the hoardings for the whole of society. It has a wider frame of reference.

So that need to be personal, person centric, but also to be attentive and think of the personal details of others. There was one quotation that I thought was really positive. In the section on the end of life and dying, it said, "At the end, dying does not mean that our early earthly life has little meaning, or should not be lived as fully as possible.

I felt that was so encouraging. I was at a conference with the SVP last week, where there was a presentation in one of the workshops on caring for people through the process of depression and dying. And the issue of the numbers in Britain. It was Danny Dorling who presented a graph of the numbers of Britain applying to go to Dignitas because they feel their identity is gone and they're written off. This was the statement in this book: "Certainly Christians live in the hope of fullness of life as eternal life in friendship with God. Nevertheless, this does not mean that our earthly line has little meaning or should not be lived as fully as possible. Moreover, to believe that a life is useless or burdensome fails to cherish the life we have been given. Indeed, the process of dementia is a part of the gradual unfolding of the mystery of our life and life unfolds in relationships." I didn't think there could have been a better summary of the theology of the whole issue than that statement. And so what I have to take from this book, Journeying Together, is that it's about much more than being particularly specific to the focus on dementia, great though that is. It has a much wider reference for all of us to help us learn, to live together, and to relate to other people. And that wonderful statement. Again, positive, "Those who live with dementia love and are loved by others." Again, a statement to go on the hoardings, a generic statement, but how deep and theological is that statement?

And then, perhaps finally, “Dementia friendly communities,” there was a lovely expression, suddenly you're reading through the chapters and you hit, hit the expression, “start somewhere.” And I thought, wow, wherever you are, start somewhere, break in, pitch in. And there was this phrase about, “We need people to tell their stories, to explain what they would like. Undoubtedly the stigma with dementia makes any disclosure difficult. But we must start somewhere. And as all our stories have shown, the generosity of people who are willing to share their stories will build better communities. That stories of those circumstances build in better communities.”

And a final word on spirituality. Because many books of advice don't include the dimension of spirituality. But what I found in this book was a definition of spirituality. on page 148. “The invisible life of spirituality is often described as the way in which someone finds meaning and connection, and find sources of hope in our world.” In other words, opening up the questions of spirituality, the questions of the meaning of our lives, the meaning, the connection, and the hope. I just hope that this book can, that you're planning for a print rerun, because I hope we can go and tell people to get it and read it in every walk of life, every age group, whether they feel that dementia is relative directly to them and their families or not, within this book, there's a rather deep theology about the nature of our relationship with each others, and I think it's something that all of us needs to learn from and to work with, but thank you to Joe and Pia for such a deep book. Sometimes academics what's the line? “Everyone's got a good book in them.” They give their whole life to it. The book comes out while Joe's been working away with his deacon work. The book's here, and he can say, I've done it now, I've published it. No, he can't, because this book must not remain on a shelf. Thank you to Joe and Pia, and let's make sure we spread the word about this book. Because it really is what may be called good news.

*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.*