

*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 third of three podcasts, and in this one we'll hear a response by Dr Helen Reid, Director of Leeds Church Institute.*

Thank you. I'm going to start on a really high note. I'd like to say congratulations to Joe and Pia. It's a massive achievement to write a book, I think it's a labour of love to get to the end, and Sister Janet who was helping with the editing, that's such a crucial role. So much work's gone into this, and it is a labour of love, I think there's love woven into this book. I really enjoy reading, I call this pastoral theology, I love a good pastoral theology book. This I think is very important for me to have read because when I read it I don't just learn about accompanying people living with dementia, you actually learn about your own spiritual journey, it's actually a way that you learn about discipleship. So I think this book should be read by everyone, not simply by people who perhaps have a direct reason because they know and love someone or they care professionally for someone who has dementia.

So there are an estimated 8,700 living with dementia in Leeds. The context I've heard for that is there's about 9,500 streets in Leeds, so if you think about the average street, there is going to be a person living with dementia on that street, so the street you live in, the street you're walking down, and if you consider the age profile of a lot of our congregations where we have more senior members, we can be absolutely sure, in the congregation where you worship on a Sunday, there will be people living with dementia. So this book is really relevant, it's really timely, and it gives us great insight into how to live well, and that's a phrase that's been mentioned.

A key part of the book for me is it's written for people who care, people who are carers, whether they're family, or clergy, or professional care support. And as portrayed here, care isn't something we do to others, because caring involves the carer and care receiver in a relationship, so it's got more of an organic feel, it's not a service, it's a relationship, and I think that's beautiful. I think the other thing about this book is it does face very honestly the pain and the joy. It doesn't hide from the difficulties, but it does also celebrate the joys. Now knowing that I was coming last in the presentations, I've had to edit little bits out of what I was going to say, but the favourite bit I was going to share, or one of the favourite bits, it's ok you haven't heard about this bit before, so I'm going to mention this. And it starts, you might be wondering what this picture's doing here. Well this is my response. In the book it says remember when it comes to caring for people with dementia, all senses count, whether it's touch or taste or smell or feel, so I thought well I'm going to do something visual. If you look at that, you might even be able to imagine a sense of smell, from that curry. This is a photograph taken by a local artist, of her mother offering a bowl of daal.

So that's a really nice image, but where I'm going to start is with the pain, it's not with the joy. And I'm going to just read from page 81. At which point I've realised I've left my glasses over here so give me a minute... So this practical advice about weight loss in dementia: "As dementia progresses, weight loss becomes inevitable, and this is not necessarily a sign of neglect," – important safeguarding point – "The very activity of eating may become a chore, the choices of food may be overwhelming, people may forget to eat, forget that they've already eaten, forget to drink sufficient fluids. They may no longer recognise tastes or textures, or that what they're being offered is food. They may have a sore mouth but not tell carers." And to me that's a bit about life closing down, because to eat a good meal is one of the great joys in life, is something really special, it is lifegiving,

physically, but also in terms of how we feel about eating, so to me that's facing very honestly the pain that a lot of people's experience of dementia, it's joy taken away, and it feels like health taken away.

So that faced very honestly and practically the sadness, but just on the next page, this is where the curry comes in. It's talking about a carer, Sue, who cared for someone called Joan. "Sue saw that Joan enjoyed eating curry, something she has always previously refused. Some textures seemed to cause problems, such that Joan would spit out things like peas, carrot pieces and beans. Mashing these vegetables helped – they did not feel like inedible objects." And so that to me is a joyful moment because Sue this carer has thought very carefully about lots of things, about how to tempt appetite and encourage people to eat, and has even been brave enough to give Joan something that she kind of knows Joan's never liked, and Joan, who's been experiencing this narrowing down of all her food options, suddenly comes into a place where she gets to enjoy something new, something she's never enjoyed before. And I thought how wonderful, out of that care and that attention to detail, something very special was happening. And it reminded me, we know that when Jesus sent out the 12 disciples, he tasked them: "Proclaim the Kingdom of heaven is near, heal the sick," and there were other things too, but the key points are that in that inheritance we are called to proclaim salvation and healing. And largely we think about, in the headlines, we think internal life and we think complete healing, but for me that moment of a carer just trying to give someone that little bit of something different, and having in that moment something very pleasurable and health-giving, to me that was just a taste of the kingdom of heaven being near, that was salvation and healing right there. So that's happening here in Leeds, in this time and this place, and it speaks to the pain and the joy of accompanying people living with dementia.

So in this book I think you'll find lots of that, I think you'll find honesty, and you'll also find the tenderness.

When I was planning a response I actually asked a colleague that we often work with, Hannah Stone, who is our poet theologian at Leeds Church Institute, could she offer a poetic response to the book, so again, thinking about the different senses and the different ways of looking at things spiritually. As background, some of you may have heard Hannah speak at later life events, and you might know that she has been a carer for three different people, her mother, her father, and a friend's husband, who has experienced dementia. And in her thinking she addressed the sadness that can come with living with dementia, and the sadness that can sometimes come with caring for someone with dementia. And we know that in our sadness the psalms are a great resource when we lament, so she's written a poem inspired by the psalms, and she's called it 'A Psalm for those Journeying Together With Dementia'.

Lord, you have searched for me and know me as I am.  
If I feel lost, you can find me, still.  
You understand the thoughts of my heart  
even when words escape from me.  
You perceive the way I have in mind  
when my friends cannot see the road ahead.  
You pick up the fragments of my desires,  
provide loving hands to weave these threads  
into garments to protect me.  
Even if I forget to praise you, your faithfulness  
feeds me; you remember my history,  
and share all my discoveries.

Lord, you search with us, and know how we long  
to make smooth the path for our companions,  
sweeping away the obstacles that trip them up.  
When we are bruised and feel broken,  
you soothe us with your wounded hands;  
when our heads ache and spin,  
you lift from them your crown of thorns.  
When loneliness closes us in,  
your presence opens new doors. When we stumble,  
you are there to steady our steps.  
The knowledge of you shines on our high spirits,  
and brightens our lowest moments.

Lord, you will always know your sheep and search for them,  
the ram, the yearling, the ewe, and lead us  
to the fold, safe from the wolves of the world.  
You will place your laughter in our mouths,  
even as our eyes shed your tears.  
You nourish us at your table,  
and refresh our thirsty souls with grace.  
We are yoked with you in a trinity of care –  
needed, given, received.  
All the day long, you walk with us,  
and when the night closes in, and darkness falls  
there you are, beside us, our place of rest.

*Hannah Stone, poet-theologian to Leeds Church Institute , June 2023*

*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](http://www.rpbooks.co.uk). This podcast was edited by Matt Collins of online events and the music was by Audio Coffee from Pixabay.*