

Here with Us

A Parish Guide to
Welcoming People
with Dementia

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Contents

Confronting Reality: <i>What's the problem here?</i>	7
Jesus Knows Our Reality: <i>Reading the Gospel for dementia</i>	11
The Reality Code: <i>What science tells us about dementia</i>	19
The Caring Reality: <i>Why we care</i>	33
Real Planning: <i>How to begin acknowledging parishioners with dementia</i>	39
Reality Out There: <i>Where to find those who need you most</i>	45
The Architecture of Reality: <i>Getting your building dementia-ready</i>	51
Real Liturgy: <i>The source and summit of caring</i>	59
Physical Reality: <i>Health is our collective concern</i>	67
The Reality of Care: <i>Beyond the patient, who we're helping</i>	73
Real Dying: <i>The new legal and cultural landscape</i>	79
Really Caring: <i>Courage in our encounter with dementia</i>	89
Sources	94

Confronting Reality

What's the **problem** here?

The statistics speak for themselves.

Every year another 76,000 Canadians are diagnosed with some form of dementia. In 2020 there were over half a million Canadians with dementia. By 2030 there will be close to 1 million. More than 7 percent of Canadians will at some point live with dementia.¹ In the year 2036, 3 percent of all Canadians alive will have a form of dementia, to some degree.²

In the U.S. nearly 6 million people are living with dementia now, and it counts as the sixth leading cause of death. By 2030 there will be 8.4 million Americans over the age of 65 living with the most common form of dementia, Alzheimer's. By 2050 it will be 13.8 million.^{3 4}

American doctors are overwhelmed. In 2020, primary care physicians reported that 40 percent of their current patients were 65 or older. On average, 13 percent of those older patients had been diagnosed with dementia. There are still doctors – 22 percent – who say they had no residency training in treating patients with dementia. But even worse is the fact that more than half describe their dementia training as “very little.”

So they refer to specialists, when they are available. More than half (55 percent) of American doctors told an Alzheimer's Association survey that there aren't enough doctors in their area to meet the demand.⁵

The World Economic Forum projects that by 2050, there will be 152 million of us worldwide living with dementia. By 2030, the health care cost of caring for this one category of illness will top \$2 trillion. If dementia care were a country, it would be the world's 18th-largest economy.⁶

We live longer, but we don't necessarily live better. One quarter of Canadians will be older than 65 by 2036. Over 50,000 Canadians with dementia right now are living in hospitals.⁷ This is not ideal. In 2020, two thirds of nursing home residents had a diagnosis of dementia, and nursing home staff are ill-equipped to care for them.⁸

Does the church care? Jesuit Fr. John Siberski, a medical doctor in Boston who specializes in geriatrics, thought one good measure of how much the church cares might be to see how many seminaries and theology faculties in English-speaking North America have programs or courses to prepare priests, deacons and lay ministers to engage the elderly – precisely the people who take up the most space in Sunday morning pews. He couldn't find one.

“They've all got courses in youth ministry. You can major in youth ministry. Not one place had even a course on the elderly,” Siberski told me.

Deacon Matt Dineen, who describes himself as a “dementia champion,” occasionally takes his wife, Lisa, to Mass in Ottawa. She lives apart from her family in a long-term care facility with a severe early onset form of dementia. Lisa sometimes stands when everyone else is kneeling. She sometimes vocalizes (she no longer speaks) in response to what's happening around her. Dineen has just about had it with the looks his family gets from others up and down the pew.

“I just wish the people around would say ‘OK, she has dementia,’ and that they would be fine with that,” Dineen said. “I would like to see dementia-friendly Masses. I know that’s probably a way off.”

“Most churches will have people with dementia in their congregations. They would like to help, but they don’t always know how,” said Fay Sampson, the British author of the 2017 book *Prayers for Dementia*.⁹

Sampson has seen parishes ignore people with dementia simply because they don’t know what to say or how to behave with people whose memory problems have begun to interfere with ordinary thinking and conversation.

“It’s important to seek out those with dementia and talk to them, because they find it harder to initiate conversations than they once did,” Sampson said.

Nobody is asking parishes to solve society’s looming dementia crisis. Parishes are not health care institutions. They are not governments, which could fund community health services. But parishes cannot sit this out, hoping somebody else solves it. They must play their part.

“It comes down to that whole essence of the mission of the church,” Catholic author and retired health care leader Michelle O’Rourke told me. “You know, we’re preaching and teaching and healing. We forget that healing part.”

If Jesus spent most of his ministry on earth healing the sick, can parishes really turn around and say healing is somebody else’s business?

The great Sr. Nuala Kenny – Order of Canada, physician, professor of medicine and founder of the Dalhousie University department of bioethics – tells anybody who will listen about the difference between healing and curing. Curing is just about the mechanics and biochemistry of our bodies – adjusting elements

of our physical being for more efficient and effective performance. Healing brings our very selves into alignment with creation around us and its creator. For a Christian, healing does not so much bind our wounds as bind us closer to God, making us whole. That's what Jesus did and still does with lepers, the blind and the outcast.

At the Alzheimer Society of Canada, they want to help. They run a program to train volunteers and community leaders in dementia issues – how to make their buildings and their programs ready to welcome those with dementia. It's called the Dementia Friendly Communities Initiative.¹⁰ They've had some interest from individual United Church, Presbyterian and Anglican congregations. They've never had a single phone call or email from a Catholic parish or diocese, according to Alzheimer Society of Canada spokesperson Roseanne Meandro.

In the U.S., the Alzheimer's Association¹¹ has created a network of hundreds of faith ambassadors who connect their churches with local community resources. The association also sponsors "Shedding Light" breakfasts, where clergy and community leaders learn about the disease and ways they can support families.¹²

If you feel you need help, you're right. The task is immense. The good news is that help is out there. It is hoped that this book will help your parish figure out what help it needs and where it might find it.

Jesus Knows Our Reality

Reading the Gospel for **Dementia**

“Just as you did it to one of the least of these who are members of my family, you did it to me,” the king says to his subjects in Jesus’ parable known as “The Judgment of the Nations” (Matt. 25:31-46).

Who is less in our society than those who struggle to remember, struggle to speak, struggle to understand? We live in a competitive, me-first kind of society that honours and rewards the smart, the quick, the ones with the right answers. As this disease takes hold, the familiar becomes unfamiliar. People among us with dementia become strangers – strangers to themselves, strangers to those who love them, strangers to the world.

If we take Jesus’ parable seriously, it is the strangers who are at the centre of the story. Whatever happens to the strangers is the measure of who we are. What happens to strangers among us happens to all of us. We are judged by our treatment of strangers, and we don’t want to “go away into eternal punishment” (Matt. 25:46).

The section of the Gospel of Matthew that culminates in this parable is set up to answer a question. “What will the kingdom of heaven be like?” However, the answer isn’t in the parables. Jesus

answers this question with his life, his passion and his resurrection. These stories are instead preparation for the drama to come.

The kingdom of heaven is like a life that has endured suffering, injustice and death but rises again to be with us always.

In this series of three parables that take up all of chapter 25 of Matthew's gospel, each story ends in a harsh judgment, then final and unforgiving banishment. Five wise bridesmaids refuse to share their oil and send the foolish bridesmaids away on an impossible search for lamp oil in the middle of the night (Matt. 25:1-13). The careful and cautious steward of a single talent of the king's gold is upbraided and thrown into outer darkness for doing precisely what an honest steward is supposed to do – holding onto the king's money and keeping it safe (Matt. 25:14-30).

Ultimately, we get this king, who divides the population between the deserving and the undeserving, the good and the bad. "I was a stranger and you did not welcome me, naked and you did not give me clothing, sick and in prison and you did not visit me," he tells those on his left. The king accuses these people, then condemns them to "eternal punishment" (Matt. 25:31-46).

Let go of the idea that this king is God. Most of us have heard too many sermons that mistake parables for allegory. This king is an absolute authority unto himself, as kings are. When we let go of this notion of the king as God, dividing and condemning, it frees us to imagine ourselves hearing the story for the first time. It frees us also from a distorted, inadequate image of God. We are free to ask, how do we see ourselves in the story?

Do we really believe that the kingdom Jesus came to inaugurate will be a place of harsh judgment and immediate exclusion? No, that's our life now – or at least it is the lives of too many of us. The point of Jesus' last parables in Matthew's gospel is to force us to recognize this cruelty. As he spins each tale, Jesus forces us to choose sides. Do we identify with the foolish bridesmaids,

sympathize with the beleaguered and cornered steward, recoil at the accusation that we have betrayed the king's family and fear the judgment that is to follow?

I can't help but think, "I don't want to be the one sent out into the darkness with no lamp oil, or humiliated by the king just for doing my job, or punished for being unable to solve problems the king should have solved." After all, if these naked, starving, thirsty people in prison are members of the king's household, then why didn't he protect his own family? Why do I have to do it for him? I don't have the king's unlimited power and resources.

Jesus tells these stories because he wants to remind us of how we have been cast away, humiliated and abandoned – how we have been judged. He wants us to feel that sting of judgment and the outrage of being accused by arrogant and careless people in power. He wants to remind us how quickly and easily the powerful dispose of people and problems. He wants us to remember who we are – we who have been humiliated, judged, pushed away and ignored.

Imagine being part of Jesus' audience – whether in the courtyard of the temple or a village synagogue or a dusty marketplace under Roman guard. We look around and see ourselves as one of the judged, surrounded by others who share our fear and shame.

As Jesus tells that last story, I think he knows his audience all want to identify with the good, honourable people on the king's right (the sheep). But at the same time, we fear we might be more like the selfish, dishonourable people (the goats) on the left. But what if we are neither? What if we are those tired, thirsty strangers who arrive in town without a cloak to keep warm? What if we're the people who fall ill or are thrown in prison? These forgotten members of the king's family are voiceless in the story. Have you felt voiceless? Silenced?

Now imagine you are living with dementia. Have you been humiliated, judged, pushed away and ignored? Are you a person

who gets treated as a problem, the way the foolish bridesmaids and the cautious steward have been? Are you dependent on the whims of either the honourable people on the king's right or the dishonourable ones standing to the left?

I believe the people with dementia in our communities are in fact more like the king's starving, naked family, left hungry, thirsty and alone by some, but clothed and fed and kept company by others. Like the king's family, they have no choice to make. They are voiceless – either chosen for welcome and hospitality or not chosen at all. It's a precarious place to be, waiting for the king's final judgment.

There is hope hidden beneath this painful experience. These parables prepare us for Christ's passion. After he tells the crowd stories of arrogant kings and mean teenage girls casting ordinary people out into darkness, he tells his disciples what will happen at the Passover – how he will be accused, humiliated and unjustly punished (Matt. 26:1-2).

Is that hope? It is for us who know Jesus alive with us and in us. The passion cannot be separated from the resurrection. If you bought this book, you are searching for resurrection in your experience of suffering through your own cognitive decline or as you care for someone with dementia. You believe the resurrection is here, now and in the future, for yourself and for your parish as it embraces the suffering of those with dementia.

The people in your parish with dementia aren't a problem best left in outer darkness or cast aside. They are still human – more human and more Christ-like – through their suffering. They are often imprisoned in a shrinking world, defined by the few places they can safely navigate and the fewer and fewer people who will ever stop to say hello.¹³ Whether they have lived perfect or imperfect lives, whether they were geniuses or not, they have done nothing to deserve the chains now draped across their minds.

When these parishioners look around during a long homily, what do they see? Do they see a community that is there for them? Or do they fear a crowd of careless, angry tyrants sending them into outer darkness? Is the crowd around them holding itself back, hoping they will never face judgment?

We are not such tyrants, we hope. Nor cowards hoping judgment falls on others. Our parishes are full of genuinely good people. As a parish, we need to examine ourselves and our relationships – not for the sake of our own purity or salvation, but for the sake of the kingdom Jesus proclaimed to us.

Jesus asks, over and over, who is our neighbour? Who is the stranger among us? Who is blessed and who is cursed? In the Sermon on the Plain, Jesus shocks us with how he defines the cursed.

“But woe to you who are rich,
for you have received your consolation.

“Woe to you who are full now,
for you will be hungry.

“Woe to you who are laughing now,
for you will mourn and weep.

“Woe to you when all speak well of you,
for that is what their ancestors did to the false prophets.”

(Luke 6:24-26)

Have good Catholics just been cursed by Jesus? I hope not. We are here to bless the frail, elderly, confused woman sitting alone, one pew over. So how do we do that?

At the altar, the priest lays out bread and wine, prays in words handed down from Jesus before he faced his torturers. The priest lifts the chalice, lifts the bread. It is the real presence. It is Christ here and now among us. This is what the kingdom of God is like, and it's real.

Reality, whenever it touches us, demands of each and every person responsibility. When we really become a mother or father, really become a husband or wife, we must take responsibility for our lives and for each other. All our sacraments are part of the larger reality of Christ's real presence in the eucharist. The real presence on the altar is the gateway to any Christian understanding of reality and Christian responsibility. There it is, the kingdom of God.

So our responsibility to that stranger down the pew who keeps opening and closing her purse, looking up and down the aisle, frozen halfway between kneeling and standing, is to be the real presence for her and with her. Dementia demands the real presence of each and every one of us, the real presence of all of us together, to reconstitute the presence of God in her life.

Can we do this? Can we take a pass and hope somebody else, better qualified and better trained, will take it on? If we try, who will tell us whether we have succeeded? How much real presence will be enough for her? What if we are not real enough, or present enough, to reconnect her with the world she once knew and understood?

This book, this author, can't definitively answer these questions. They are what church professionals call eschatological questions. They concern the end times, the sum of all things, the ultimate. All of us live in the midst of final judgment, but we are not the judge. We have no business guessing at the judge's last dispensation.

But we should be assured that ultimate solutions for dementia, just like the ultimate healing of the world, are up to God. He is the end-times judge and we trust this judge. Our judge has been judged, condemned, crucified. He is one of us – we who wince at the harsh judgments in those last parables of Matthew's gospel. He is present with and in each person with dementia. Are we willing to be present, really present, with Jesus? Will we play our part?

It's a hard part to play, not knowing how much good we're doing or how to fix the problem. We would prefer certainty. In the 21st century, we have mostly chosen to reason, to analyze and to know the answers. We want to be right. We measure ourselves by how often we have the right answer. We shun the contagion of wrong answers, half answers, confusion and forgetfulness. This preference for clarity and precision, hard facts and science, is not wrong. But it's not enough.

What is enough? The kingdom Jesus announced in his life and in his resurrection is enough. The real presence of Jesus, here and now in your parish, is enough for parishioners with dementia.

As you read what follows, begin to think of a parish dementia committee. Begin to imagine how your community might practically, concretely choose life and length of days for each other. Imagine your parish really present in the lives of its weakest and poorest members.