**Building dementia-friendly parish communities after Covid 19**

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Undoubtedly, one of the lasting images of 2020 was of tearful families separated from their loved ones living in care homes, able only to press a hand against the glass between them. The look of confusion, bewilderment and abandonment on the faces of people used to real touch, real hugs, real contact, was palpable. Some of these people had dementia, all of these people had to try and make sense of a new reality. For perhaps the very first time, the person with dementia came to the attention of the press not as a statistic or simply a tragic figure, but as someone’s mother, father, wife, husband. Someone loved and missed. Someone with a life that can be lived well. The clear message was that people with dementia have fulfilling relationships, they have real human needs, and when these needs are met, they can live full, flourishing and happy lives. Covid has tried to rob people of this. These were not one-off anecdotes but the experiences of many families. It seems that it has taken a pandemic to throw the spotlight on what has possibly been inaccurately described as a silent pandemic: the lived reality of dementia that does not simply target the elderly; the tough decisions that families have to make simply to keep their loved ones safe; the lack of joined-up thinking that isolates health from social care and community support.

Dementia is not a pandemic. It is not contagious, and it is important to point out that most people will not develop dementia. But its reach and effects are widespread. Covid 19, no respecter of persons, has taught a population that had not been renowned for its fascination with statistics, to pay attention to daily data of infections and deaths. Dementia too has its data, no less striking, to offer. There are estimated to be in excess of 50 million people living with dementia globally, with someone developing the condition every three seconds.[[1]](#endnote-1) The UK data is equally thought-provoking, with around 850,000 people living with the condition, and someone developing dementia every three minutes.[[2]](#endnote-2) Dementia is the umbrella term for a range of diseases of the brain of which Alzheimer's and vascular dementia are perhaps the most well-known. Dementia causes symptoms such as changes in mood and behaviour, memory and communication difficulties, and gradual loss of control of many physical functions.[[3]](#endnote-3) There are cases of early onset and it is not solely or necessarily associated with old age, though its incidence increases with age.

Covid has brought with it a host of bad stories, of failures in the vital provision of PPE, failures adequately to protect vulnerable people, action that is too little too late. However, there have also been inspiring stories of care, creativity and solidarity. Pope Francis reminds us that story is an essential part of our lives, and that we need good stories to edify, to emulate, to inspire.[[4]](#endnote-4) So it is perhaps opportune, whilst we live through the Covid 19 global pandemic, to consider how the Church might develop helpful and inspiring practice and true stories about dementia, this other condition of global impact and proportions.

**See, judge, act**

The Church, with its teaching on Catholic social justice, with its preferential option for the poor, with its sacramental strength, is perhaps uniquely placed to reconsider how we, as Church, can bring comfort to, and draw inspiration from our brothers and sisters living with dementia, both now in the interim, and later in our ‘new normal’. The traditional approach to issues affecting the life of the Church is to examine the signs of the times, and then to ‘see, judge, and act’. In terms of how we might approach the dilemmas posed by dementia, in this world affected by Covid, this three-phased approach is indispensable. For Pope Francis to ‘see’ is to journey together to understand reality with the eyes of faith and heart of God. People with dementia and their families are essential participants in this journey and their voices are crucial for developing an authentic understanding. To ‘judge’ is not to judge individuals but to discern the situation according to Jesus Christ, Way, Truth, Life, where every human being, no matter his or her condition, is a unique and irreplaceable person with full human dignity, a child of God, and our brother or sister. The call to ‘act’ rescues the method from being simply a ‘paper exercise’. To act is from the Church in spreading the Kingdom. To act is missionary and it is evangelization. Everyone has a part to play in evangelization,[[5]](#endnote-5) and that includes the person with dementia. Additionally, Pope Francis recognizes that people need a specific quality today: that of *parrhesia*, apostolic zeal marked by the characteristics of humility, prayer, and listening ‘with humility and welcome, and with an open heart.’[[6]](#endnote-6)

**See**

To see the situation at a more local level, which is where parishes primarily act, it is perhaps important firstly, individually and collectively, to gain an understanding, both theoretical and practical, of what dementia is, and what its stages are. Certainly, dementia affects everyone individually, and it is important to focus on the individual. There are, however, generics and dementia is a terminal disease. Everyone needs to be informed of moral and ethical issues, especially end of life issues, including palliative care, life-sustaining treatment (and its continuation or withdrawal). Certainly, we cannot all be experts in dementia, but people involved in church life have the responsibility to know the basics and to know where to turn for advice.[[7]](#endnote-7)

As well as seeing, and having some understanding of the *disease*, it is next important to see the *people* affected by dementia. Unless we have an awareness of who in our parish and local community is touched by this disease it is difficult to reach out to them, to offer them support and comfort, and indeed to learn from them. This is a difficult and sensitive phase of seeing. There is still, sadly, stigma attached to dementia, for people pre- and post- diagnosis, for their family, for their friends. Moreover, parishes have always had difficulties keeping in touch with parishioners, and this is especially the case when someone moves into a care home or stops attending their usual mass. Forming parishes into supportive communities with a mission for outreach is an indispensable part of the church’s missionary and evangelizing activity. Sometimes challenging situations become kairos moments, critical moments causing us to reflect on what we can and should be. While mindful of the requirements of data protection and safeguarding, priests and those active in the parish need to know their parishioners well in for people to express concerns, to seek advice, and to feel safe in expressing emotions from anger to bewilderment to quiet despair to guilt to loss.

Each parish will have different approaches to *seeing* where dementia impacts on the lives of, for example, young onset parishioners, who, with minimal support, can still be very active members of the parish, maybe reading at mass or visiting the housebound. Others touched by dementia include families of elders who have dementia, parishioners who are professional carers (both domiciliary and institutional), housebound elders living alone with dementia symptoms. Part of the parish process may involve making it possible to speak about dementia, through homilies, through examples, through inviting speakers. Once the taboo of speaking about dementia has been addressed, at least partially, it will be more possible to *hear* what needs to be done. People with dementia will have differing needs, as each of us is an individual at different stages of life and of development. Formal and informal carers will also have varied needs as will friends and family members. All need, as a minimum, to feel validated and allowed to find a welcome in the parish.

**Judge**

Once we feel that we are aware of what the needs and hopes of those affected by dementia in the parish are, we will be better equipped to move to a situation of discernment. We will be able to *judge/discern* the parish response, and how to involve people with dementia in the life of the parish, as well as how to involve their family members and carers. It is important at this stage to acknowledge that this is not a case of ‘us’ enabling ‘them’ to ‘join in’ on our terms. Everyone has a place, and it does not rely on ‘us’ to ‘make room’ for ‘them’. Rather this discernment offers a moment of humility and reality to acknowledge failures, inadequacies and often simply myopia. This stage of discernment will need to involve prayer and reflection on how we all might view dementia. This discernment opens up very many interpretations that may encompass fear and suffering through to acceptance and perhaps even joy in a relationship seen in a new reality. But how we see dementia should never obscure how we see the person: someone with full human dignity, someone loved, someone who is loved by God as His special creation and, please God, destined for eternal life with Him. In this discernment we should not sidestep difficult questions of suffering, fear, anger or even grief and a sense of loss. We do not need to avoid these questions precisely because the Church has insights and resources that allow us to reflect deeply on them. One particularly rich insight concerns suffering. While some reject the term ‘dementia sufferer’ because they feel it objectifies them, and predisposes others to pity, it is important to come to terms with the element of suffering which touches the lives of those who have dementia and those who support them. As Pope St John Paul II points out, suffering is part of the human condition and although suffering remains a mystery, in the final analysis we can entrust all our sufferings to Christ, the Wounded Healer who binds up all our wounds.[[8]](#endnote-8) Church insights, notably from her social teaching, remind us that everyone has a part to play in our communities, and that building up the community is an act of solidarity. People with dementia witness to the significance of being in the present, of realising that we are dependent, interdependent, and fragile beings, that there is a deeper meaning to being human. This witness to our common humanity is especially important for societies that seem to be eager to write off certain people as unimportant, even expendable.

Discerning judgment is also relevant for moral issues. Decisions about treatment, notably when to cease treatment which might be over burdensome for the person with dementia happen on a daily basis. Church teaching can help people to inform their decision-making.[[9]](#endnote-9) Moreover, the Church has a right and duty to speak with and for those whose lives are touched by dementia.

How then to make a parish community dementia aware and, subsequently, dementia friendly?

**Act: developing a dementia friendly community**

The stage of *discernment* may have led to many questions about our own faith and its foundations. This is an important part of our own journey with those whose lives are affected by dementia. We are always called to deepen our faith and spirituality. Developing resources to work with people with dementia can be fulfilling for everyone. There is real scope here to work with stories from scripture and the saints and, where words become difficult, with the rich resources of art and music that often bring out a depth beyond words.

There is a growing resource of literature and experience from parishes that have adopted development programmes, and awareness raising initiatives for dementia. Among many resources are the individual or group programme *Welcome me as I am*, developed by Caritas Social Action Network,[[10]](#endnote-10) the Liverpool Diocese action plan to develop dementia friendly churches,[[11]](#endnote-11) and Growing Old Grace-fully organisation that has helped the Diocese of Leeds develop dementia friendly communities. It is also, important, however, to listen to parishioners who have dementia, and to those who care, formally and informally. They will know what support they can offer to others, they will have awareness of what they need of the parish, as their family and local faith community. Some with dementia will have been going regularly to Mass and the Sacraments before the pandemic. Some may have been in care homes, unable to receive visitors, unable to pray in company with the family, priest, Eucharistic minister. Some may have been living alone, housebound, deprived of informal visits, and of regular Communion. Many of these people may have had a deterioration of their dementia symptoms during the pandemic. The people who have lived through isolation and deprivation of contact may have ideas about how they could have been better supported, and what they found useful during the pandemic, whether it was online Mass, outdoor Communion and reconciliation, family prayers, a phone call and a prayer said together with a parish pal. They will certainly know how post- pandemic parish support for families living with dementia might look.

Action also requires awareness of available resources and a recognition that many priests are themselves ageing and vulnerable. Post pandemic salaried parish teams may no longer be possible because of lack of funds. It is important to be realistic about what can be done, and by whom, before drawing up ambitious action plans which falter and cease, and, consequently, leave those very parishioners we had wished to involve feeling even more bereft than before. If the Covid pandemic shows us anything, it is that we are beings who need community, who need warmth and affection. Of course, people with dementia and their families always knew this. We have learnt what we valued and hitherto took for granted by cruelly being deprived of it. Re-connecting people to their communities can take place on different levels but simple things like a telephone call can make all the difference, and when contact becomes possible again, a hand held to show warmth and understanding. The involvement of young people from local primary and secondary schools, perhaps *confirmandi*, (subject to relevant safeguards), and people of other faiths, through for instance visiting care homes, sharing activities especially singing, and showing real interest in people’s stories using perhaps memory boxes, benefits both the young and the elderly. Naturally, this cannot be forced and there cannot be a one-size fits all approach, after all some people may not like music or may find children annoying. Memories may be painful or may cause frustration. Moreover, account should be taken of people who cannot stay in one place for too long, for people who simply want to walk, and for people who frequently have overwhelming emotions.

All this comes down to personal engagement with people that generates trust, openness and creativity tailored to individuals. Parishes may also find it fruitful to create their own stories about how to help and be helped by families living with dementia. Small and large interventions, appropriately anonymised and with the consent of those involved, may be recounted in newsletters, on websites and at parish, deanery and diocesan level. The journey to the creation of dementia friendly parishes will be as varied as parishes themselves and good practice already exists. Sharing that practice and sharing both the realities of pain and joy in people’s journeys will contribute to a way forward that is inspired by hope.

1. Alzheimer's Disease International (2019) *World Alzheimer Report 2019: Attitudes to Dementia,* London: Alzheimer's Disease International, p.13. [↑](#endnote-ref-1)
2. Alzheimer's Society (2020) *Facts for the media*, https:// [www.alzheimers.org/uk/about-us/news-and-media/facts-media](http://www.alzheimers.org/uk/about-us/news-and-media/facts-media) [↑](#endnote-ref-2)
3. Nuffield Council on Bioethics (2009) *Dementia: Ethical Issues*, London Nuffield Council on Bioethics, p.4 [↑](#endnote-ref-3)
4. Francis, Pope (2020) *Message of His Holiness Pope Francis for the 54th World Communications Day,* www.vatican.va>documents>popefrancis>messages>worldcommunicationsdays [↑](#endnote-ref-4)
5. Pope St John Paul II, Christifideles Laici, 1988. [↑](#endnote-ref-5)
6. Pope Francis, *To the Synod Fathers during the First General Congregation of the Third Extraordinary General Assembly of the Synod of Bishops* (6 October 2014). [↑](#endnote-ref-6)
7. For example, the Catholic Bishops Conference of England and Wales website, <https://www.cbcew.org.uk/>; the Anscombe Bioethics Centre <http://www.bioethics.org.uk/>; the Art of Dying Well project <https://www.artofdyingwell.org/> [↑](#endnote-ref-7)
8. Pope St John Paul II, *Salvifici doloris* 1984. [↑](#endnote-ref-8)
9. There are a number of resources from the Catholic Bishops Conference of England and Wales, https://www.cbcew.org.uk/home/our-work/health-social-care/healthcare-downloads/ [↑](#endnote-ref-9)
10. Caritas Social Action Network and Ben Bano,

    https:// [www.csan.org.uk/member/welcome-me-as-i-am/](http://www.csan.org.uk/member/welcome-me-as-i-am/) [↑](#endnote-ref-10)
11. Catholic Archdiocese of Liverpool, <https://www.dementiaaction.org.uk/members_and_action_plans/4623-roman_catholic_aarchdiocese_of_liverpool> [↑](#endnote-ref-11)