



# Chisholm Health Ethics Bulletin

Drawing on thorough research, the best of human insight and the strengths of Catholic teaching, we offer an ethical vision to inform modern health care. We strive to guide our readers to greater knowledge and deeper understanding about issues in health care, and to assist all people in their search for insight and wisdom.

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# In this issue

Welcome to the third issue of the *Chisholm Health Ethics Bulletin* in its refreshed, contemporary format. There are three articles in this Bulletin:

My article is an invitation to Australian Catholic aged care services to develop policy and procedures to welcome and embrace people from diverse backgrounds. The focus of this article is on persons who are lesbian, gay, bisexual, transgender and intersex (LGBTI), and, as far as we know, this is the first Australian article to reflect on care for this oftentimes disadvantaged group from a Catholic perspective. From this perspective, the call is to develop policy and procedures to welcome people from many diverse backgrounds, including people from Aboriginal and Torres Strait Islander communities, people from culturally and linguistically diverse (CALD) backgrounds, and so on.

This article is based on a presentation which I first gave at the Catholic Health Australia Ethics Education Seminar in Sydney on 6 May 2015, and which I presented again at the Catholic Health Australia National Conference in Canberra on 25 August 2015. I recently gave this presentation once more in Melbourne on 12 November 2015, this time to a group of Residential Aged Care Service Managers from Mercy Health. In each case, I have been encouraged by the positive feedback and enthusiastic support for this proposal. I hope that many Catholic aged care services in Australia do take up

this invitation.

Our researcher Emanuel Nicolas Cortes Simonet reflects on ageism and age discrimination. Ageist attitudes and behaviours can diminish an older person's sense of self-worth. This in turn can lead to social isolation, diminished wellbeing, poorer health, and reduced mental ability. Nicolas explores what has been written on this topic both from a secular Australian perspective and in the international teaching of the Catholic Church. Both these perspectives provide resources to recognise, challenge, and move to overcome ageism and age discrimination in Australia.

Dr Dilinie Herbert's article is on Dignity Therapy. Terminally ill patients nearing the end of life may experience a perceived loss of dignity, along with great distress and even despair. Developed by Dr Harvey Max Chochinov and his colleagues, Dignity Therapy is a brief psychospiritual intervention designed to conserve or restore both dignity and a sense of purpose and meaning. In this therapy, a trained facilitator works with the terminally ill person to produce a generativity document – an account of their life which they leave as a legacy. Dilinie's article also explores the use of Dignity Therapy in other settings of care.

Kevin McGovern ✕

## About the Caroline Chisholm Centre for Health Ethics

The Caroline Chisholm Centre for Health Ethics is a Catholic bioethics centre:

- We research and publish about health care issues.
- We provide education and training about health ethics to health professionals and the general community.
- Over the phone or face to face, we assist without discrimination any person who seeks help in making decisions about health care.
- We contribute to community discussion and debate by making public comments about important matters related to health care.
- We also assist health care institutions in the development of policies, protocols and procedures, particular in areas which might be ethically contentious.

Catholic bioethics is based upon both faith and reason. "Faith and reason," Pope John Paul II once wrote, "are like two wings on which the human spirit rises to the contemplation of truth." (John Paul II, *Fides et Ratio*) Thus, the long Catholic tradition contains much reasoned reflection on human experience – reflection which has discerned a natural ethic which is sometimes called the natural law. However, the Catholic tradition also contains much reflection on the wisdom which is found in what the Church recognises as divine revelation. This includes the Bible and above all the

example of Jesus Christ. Noting that Jesus healed the sick, for example, many Catholic health and aged care services proudly proclaim that they are continuing the healing mission of Jesus.

Above all, faith and reason reveal the inherent dignity of each and every human being, no matter how sick, aged, frail or disabled we may be. In the Bible, the book of Genesis records that God created human beings "in the image of God." (Gen 1:27) In the Catholic tradition, it is this *imago Dei* – the image of God which is present in every human being – which is the ultimate foundation of human dignity.

From this starting point, Catholic bioethics contributes to moral discourse in every stage of the life continuum from conception to natural death. This Catholic perspective strives to be holistic and to take into consideration all the needs of the individual – physical, emotional, psychological, social, and spiritual. The Catholic approach to care is marked by great emphasis on the importance of pastoral and spiritual care.

Catholic bioethics makes a significant contribution to the moral debates in our society that are critical in this age of advancing technology. It reminds us of our meaning and purpose in life, and guides us towards its fulfilment, not just as individuals but as people in community.

# Responding to Sexual Diversity in Catholic Aged Care Facilities

*This article reflects on the discrimination which LGBTI people still experience in Australia. It also notes the commitment of the Catholic Church to provide pastoral care to LGBTI persons. From all this, it argues that Catholic aged care services should develop formal policies and procedures for welcoming and embracing people from diverse backgrounds. This should include firm plans for the education and training of staff, and a clear mechanism for receiving and resolving complaints.*

How should a Catholic aged care facility best care for any of its residents who are LGBTI? As we will see, the Australian Government has issued a strategy about this, and various recommendations have also been made by individuals and groups particularly from within the LGBTI community. As far as I know, however, this is the first Australian article which addresses this question from a Catholic perspective. This article contains five sections. The first notes some of the terms and acronyms which are relevant to this topic. This is important because, if aged care providers either do not know these terms or misunderstand them, this could be an obstacle to effective reflection and action in this area of care. The next three sections follow a common pattern in Catholic social thought which is usually referred to as See, Judge and Act.<sup>1</sup> Thus, these sections will explore the experience of LGBTI persons in this country (See), reflect on this situation in the light of Catholic teaching (Judge), and then seek to discern the steps that Catholic aged care facilities should take so as to provide best care to any of their residents who are LGBTI (Act). A final section presents a story which illustrates the sort of care we should strive to provide. This story involves Pope Francis and a transman named Diego Neria Lejárraga.

## Terms and acronyms

LGBTI (or sometimes GLBTI) is an acronym which refers collectively to a diverse group of people who are lesbian, gay, bisexual, transgender or intersex. The term 'sexual orientation' expresses who we are erotically attracted to. Most people are erotically attracted to people of the opposite sex: their sexual orientation is heterosexual. We must however also recognise diverse sexual orientations. Some people are erotically attracted primarily to people of the same sex: they are women who are lesbian, and men who are gay. Other people are erotically attracted to both women and men: they are bisexual.

'Transgender' or 'trans' is an umbrella term which includes all people who do not fit the usual understanding of being a woman or a man in our culture. Thus, it includes cross-dressers, drag performers, those who identify as gender queer, those who identify as

androgynous (i.e. as both woman and man), and those who reject gender labels entirely.

Another diverse group of transgender people are transsexuals who experience marked conflict between their physical or biological sex and their gender identity – that is, their own internalised sense of being a man or a woman. Some in this group transition to their preferred gender. This process usually involves counselling, a change of name, and adopting the style and presentation of the preferred gender. Depending on the individual, it may or may not involve surgery. Nowadays, someone who has transitioned from a man to a woman may identify as a transwoman. She may also say that she was 'assigned male at birth.' Similarly, someone who has transitioned from a woman to a man may identify as a transman. He may say that he was 'assigned female at birth.' If surgery is involved, it may be referred to as medically assisted gender reassignment or gender affirmation surgery. (Some of these terms may not be consistent with the Catholic understanding of transsexualism. Even so, staff at a Catholic aged care facility should be aware of these terms.)

We should note that sexual orientation and gender identity are distinct. For example, a transwoman may be erotically attracted to men, or she may be erotically attracted to women. We should be careful not to make assumptions about the sexual orientation of transgender people.<sup>2</sup>

The term 'intersex' refers to people who are born with genetic, hormonal or physical characteristics which are not typically male or female. Intersex persons have a diversity of bodies and identities.<sup>3</sup>

## See

With these terms and acronyms noted, let us now explore the experience of LGBTI persons in Australia. We will consider the experiences of LGBTI people in general, and then look more closely at the experiences of older LGBTI persons. In the light of all this, we will survey the Australian Government's *LGBTI Ageing and Aged Care Strategy*.

....LGBTI people in Australia have significant experiences of discrimination, stigma, social exclusion, verbal abuse, harassment, bullying and even violence. Secondly, LGBTI people had a significantly higher incidence of mental health issues....

As I sought to understand more about the experiences of LGBTI persons in this country, I found four resources particularly useful. Two of these were *Private Lives 2* and *A Closer Look at Private Lives 2*.<sup>4</sup> *Private Lives 2* was an online survey of GLBT Australians publicised primarily through GLBT-community networks across Australia and

conducted from 12 January to 31 April 2011. Hard copies of the survey were distributed through GLBT seniors organisations.<sup>5</sup> The survey was completed by 3,835 Australian residents. *A Closer Look at Private Lives 2* drew on the same data but focussed on the mental health and wellbeing of LGBT Australians. Another useful resource was *Resilient Individuals*, a report by the Australian Human Rights Commission. This report was based on a national consultation which took place between August 2014 and February 2015, and which drew upon a number of methodologies including face-to-face consultation, literature review, a discussion paper which sought written submissions, and an online survey. The Commission consulted with more than 40 organisations around Australia, received more than 40 written submissions, and 1,518 people completed the online survey. Another resource which I found most useful was a Fact Sheet from beyondblue, *Depression and anxiety in gay, lesbian, bisexual, transgender and intersex people (GLBTI)*.<sup>6</sup>

.... Many older LGBTI people's sense of who they are is still significantly shaped by the discourse of the 1950s and 1960s, which saw them as sick, sinful or even criminal. Many older LGBTI people fear that residential aged care will once again require them to conceal their LGBTI identity....

Two findings stood out to me. Firstly, LGBTI people in Australia have significant experiences of discrimination, stigma, social exclusion, verbal abuse, harassment, bullying and even violence. For example, in the *Resilient Individuals* online survey, more than 90% of respondents knew someone who had experienced violence, harassment or bullying on the basis of their sexual orientation, gender identity or intersex status, and more than 70% had experienced such violence, harassment or bullying themselves.<sup>7</sup> Secondly – and no doubt related to the first finding – LGBTI people had a significantly higher incidence of mental health issues. For example, the beyondblue Fact Sheet reported on a 2007 national survey of mental health and wellbeing conducted by the Australian Bureau of Statistics. In this survey, while heterosexual people reported a 14 percent incidence of anxiety disorders, LGB people reported a 31 percent incidence. Similarly, whereas heterosexual people reported a 6 percent incidence of depression and related disorders, LGB people reported 19 percent. In the same way, heterosexual people reported a 5 percent incidence of substance use disorders, but LGB people reported 9 percent. The same Fact Sheet quoted other studies which found that almost 90% of transgender people had experienced at least one form of stigma or discrimination, and that around 60 percent of intersex people reported having depression.<sup>8</sup> These findings remind me that LGBTI people in Australia belong to a group which is disadvantaged and sometimes struggling.

What about older LGBTI people? I found 8 different resources which raised similar concerns and also proposed similar solutions.<sup>9</sup> I also found that the *Australasian Journal of Ageing* had recently prepared a Special Issue on LGBTI ageing and aged care.<sup>10</sup> From all this, five findings stood out to me. Firstly, many older LGBTI people's sense of who they are is still significantly shaped by the discourse of the 1950s and 1960s, which saw them as sick, sinful or even criminal. Secondly, a strong sense of fear has run through their lives. Thirdly, they have often coped by hiding their LGBTI identity. Fourthly, this strategy has often had significant personal costs, ranging from feelings of isolation to mental health issues. Finally, many older LGBTI people fear that residential aged care will once again require them to conceal their LGBTI identity. They particularly fear this in connection with services run by religious organisations like the Catholic Church.<sup>11</sup> These findings demonstrate to me that older LGBTI people entering residential aged care are a particularly vulnerable group.

As the Australian Government's *LGBTI Ageing and Aged Care Strategy* notes, the *Aged Care Act 1997 (Cth)* identifies nine groups of people who have special needs within aged care. They are people from Aboriginal and Torres Strait Islander communities, people from culturally and linguistically diverse (CALD) backgrounds, people who live in rural or remote areas, people who are financially or socially disadvantaged, veterans and their spouses, people who are homeless or at risk of becoming homeless, care leavers, parents separated from their children by forced adoption or removal, and LGBTI people.<sup>12</sup> There are also additional services for older people with disabilities.<sup>13</sup> What we have noted here eloquently demonstrates why LGBTI people are indeed one of these groups with special needs. As the Strategy itself notes, older LGBTI people are "a group requiring particular attention due to their experience of discrimination, and the limited recognition of their needs by service providers and in policy frameworks and accreditation processes."<sup>14</sup>

### Judge

How does Catholic teaching guide our response to this situation? There are at least six international Catholic teaching documents which we should consider:

- *Declaration on Certain Questions Concerning Sexual Ethics (Persona Humana)*, #8, from the Congregation for the Doctrine of the Faith (CDF) (1975),
- *Letter to the Bishops of the Catholic Church on the Pastoral Care of Homosexual Persons (Homosexualitatis Problema)*, from the CDF (1986),
- *Some Considerations Concerning the Response to Legislative Proposals on the Non-Discrimination of Homosexual Persons*, from the CDF (1992),
- *Catechism of the Catholic Church*, #2357-2359, 2396 (1994, revised in 1997),
- *Family, Marriage and 'De Facto' Unions*, from the Pontifical Council for the Family (2000), and

- *Considerations Regarding Proposals to Give Legal Recognition to Unions between Homosexual Persons*, from the CDF (2003).<sup>15</sup>

My summary of this teaching is in two parts. I note firstly Catholic teaching on matters which are possibly controversial. I then consider other Catholic teaching which though important, is perhaps less well known.

### Controversial matters

The staff of Catholic health, aged and community care services in Australia are diverse, and includes both Catholics and non-Catholics. Given this diversity, it may be that some people might not agree with Catholic teaching in some of these matters. Even so, these are the ethical standards which Catholic institutions must follow. A Catholic institution cannot take any position which is contrary to this teaching. There are four matters which we should note:

Firstly, Catholic teaching views transsexualism as a psychological problem which should therefore be treated not with surgery but with psychological counselling. Thus, the Australian Catholic *Code of Ethical Standards* states:

The first priority in dealing with adults who experience conflict in relation to their gender identity is sensitive psychological and/or psychiatric management. Positive means should be found to assist the person to come to terms with his or her bodily nature. Interventions should be limited to authentic therapies for pathological conditions. Procedures or interventions that deliberately render a healthy sex organ dysfunctional, mutilate it or remove it, as a treatment for a psychological or psychiatric problem, are not permissible.<sup>16</sup>

Secondly, Catholic teaching holds that all homosexual sexual intercourse is morally wrong:

A person engaging in homosexual behaviour acts immorally. To choose someone of the same sex for one's sexual activity is to annul the rich symbolism and meaning, not to mention the goals, of the Creator's sexual design. Homosexual activity is not a complementary union, able to transmit life; and so it thwarts the call to a life of that form of self-giving which the Gospel says is the essence of Christian living... When homosexual persons engage in homosexual activity they confirm within themselves a disordered sexual inclination which is essentially self-indulgent.<sup>17</sup>

Thirdly, the Catholic Church holds that there should be no legal recognition of homosexual unions. Thus – while some may find this statement provocative – one Catholic document holds that “legal recognition of homosexual unions... would mean... the approval of deviant behaviour.”<sup>18</sup>

Finally, Catholic teaching holds that being homosexual is itself objectively disordered:

Although the particular inclination of the homosexual person is not a sin, it is a more or less strong tendency ordered toward an intrinsic moral evil; and thus the inclination itself must be seen as an objective disorder.<sup>19</sup>

As I have said, not everyone might agree with these teachings. Indeed, reflecting on these matters may cause some people some distress. If this has happened to you, please consider speaking to the pastoral care department of a Catholic health, aged or community care service or contact us here at the Chisholm Centre. Even if there are some things about which we might not agree, it is important that we continue to speak together and to maintain relationships of respectful dialogue.

### Other Catholic teaching

There are other things which the Catholic Church also teaches. I fear that amidst the controversies these other things are sometimes lost. There are five matters we should consider:

Firstly, the Catholic Church recognises that there are people who are indeed LGBTI. This is significant because there are other religions which seem to claim that issues related to sexual orientation, gender identity or intersex status may be ‘remedied’ quite simply by prayer. By contrast, the Catholic Church does not hold this rather glib and quite inadequate opinion. As one Catholic document notes, the Catholic Church recognises that there are indeed “homosexuals who are definitively such.”<sup>20</sup> Further, it is reasonable to extend this affirmation about diverse sexual orientation to diverse gender identity and diverse intersex status. What is more, any Catholic response to LGBTI issues and LGBTI persons must be based on this Catholic realism.

Secondly, the Catholic Church holds that being LGBTI is not a sin. Sin is wrongdoing, and we can only commit sin in those areas of life which involve choice. That being said, the best evidence is that sexual orientation, gender identity and intersex status are not something which people choose, but rather something which people discover about themselves. This is why one Catholic document states that “the particular inclination of the homosexual person is not a sin.”<sup>21</sup> Once again, it is reasonable to extend this affirmation to all LGBTI persons.

...We should note that the Catholic Church recognises that there are LGBTI persons, that it opposes homophobia and transphobia, and that it commits itself to the pastoral care of LGBTI persons....

Thirdly, the Catholic Church insists that LGBTI persons have human dignity and human rights. As another Catholic document states, “Homosexual persons, as human persons, have the same rights as all persons, including the right of not being treated in a manner which

offends their personal dignity.”<sup>22</sup> Once again, this affirmation should be extended to all LGBTI persons.

Fourthly, the Catholic Church opposes homophobia and transphobia. “It is deplorable,” one Catholic document says, “that homosexual persons [and any other LGBTI persons] have been and are the object of violent malice in speech or in action. Such treatment deserves condemnation from the Church’s pastors whenever it occurs.”<sup>23</sup>

Finally, the Catholic Church commits itself to the pastoral care of LGBTI persons: “The phenomenon of homosexuality... is a proper focus for the Church’s pastoral activity. It thus requires of her ministers attentive study, active concern, and honest, theologically well-balanced counsel.”<sup>24</sup> Catholic teaching probably does need to be more explicit about bisexuality, diverse gender identity and diverse intersex status, but this commitment too can reasonably be extended to all LGBTI persons.

....My recommendation is that there are four areas which Catholic aged care services should consider: policy and procedures, respectful engagement, staff education and training, and a mechanism to receive and resolve complaints....

To conclude this section, we should note that there is clear Catholic teaching about a number of controversial questions, and that any Catholic organisation cannot adopt any position which is contrary to this teaching. At the same time, we should also note that the Catholic Church recognises that there are LGBTI persons, that it opposes homophobia and transphobia, and that it commits itself to the pastoral care of LGBTI persons. This Catholic teaching should guide us as we plan our response to the situation of LGBTI persons in this land.

## Act

I have read extensively on this issue. I am also grateful to a number of people who have shared their opinions with me. From all this, my recommendation is that there are four areas which Catholic aged care services should consider: policy and procedures, respectful engagement, staff education and training, and a mechanism to receive and resolve complaints. These are discussed in turn below.

### Policy and Procedures

Quite a lot can be done without a formal policy and procedures. If you work at a Catholic aged care service which does not have a policy or procedures in this area, I therefore encourage you to do whatever you can. Even so, my first recommendation is that Catholic aged care services do develop a formal policy and procedures which express their desire to welcome and embrace all diversity. As I have noted above, the Australian Government has identified nine or ten groups with special needs within

aged care. I do not believe that most aged care services have the resources to develop separate policies for each of these groups. However, I do believe that most aged care services do have the capacity to develop a policy and procedures on diversity in general, including specific mention of these various groups.<sup>25</sup> This may be a work in progress which is developed and expanded over time. The development of policy and procedures in this area eloquently demonstrates that we are striving to take diversity seriously. It also means that we have made certain commitments, and that we can be held accountable to these commitments.

This policy and procedures should include a Public Statement about our desire to welcome and embrace diversity. This Public Statement should be included in welcome material on intake. It should also be featured on the organisation’s website, displayed as a poster on the walls, and so on. As well as information about other diverse groups, it could include the following affirmation:

If you are lesbian, gay, bisexual, transgender or intersex (LGBTI), you can speak with us about this. It can take courage to do this. Even so, it helps you to feel at home, and it helps us to give you the best care. One person you can speak to is \_\_\_\_\_.

The policy and procedures should also explain the organisation’s practice for offering shared rooms to same-sex couples. I have argued elsewhere that making such an offer is not inconsistent with Catholic ethical standards.<sup>26</sup>

In addition, the policy and procedures should set out the organisation’s commitment to educate and train their staff about diversity. It should also detail the organisation’s mechanism to receive and resolve complaints in this area. I will say more about these two areas below.

### Respectful engagement

While I have seen this suggested, I do not believe that there should be a standard question about LGBTI status on intake. My advice is that there is too much risk that this might cause some people to lie. At the same time, intake staff should know how to respond if someone does disclose their LGBTI status. At this point, uncomfortable silence or an inappropriate response could do considerable harm, whereas an appropriate response could do much good. For example, the intake staff could say, “Oh, I’m so glad you told me! At XYZ Care, we try hard to welcome and embrace diversity. Now, I’m not the expert here, but \_\_\_\_\_ is our Diversity Officer, and she’s really lovely. Would it be ok if I told her what you said, and asked her to have a talk with you?”

When I have spoken about this issue, some people have suggested that we need not do any more than I have already described. However, I have heard and read several stories in which the respectful engagement of care staff has helped someone who had not disclosed their LGBTI status to do so, or in some cases to reveal a secret which they have hidden for all of their life.<sup>27</sup> One of the

strengths of Catholic aged care is our pastoral carers, and many of them would be natural leaders in this respectful engagement. Sometimes, as they get to know the residents, they may begin to wonder about someone's LGBTI status, and they may decide respectfully to ask. It is important that this question should not cause someone to lie. For example, they might say:

I have a question to ask you. But I want to check first if it would be ok to ask this question. It's a question about your sexual orientation – whether you might be lesbian/gay. I don't want to ask this question if it would make you uncomfortable. So let me ask first if it's ok for me to ask this question.

In some cases, someone will make it clear that they do not want to answer this question, at least at this time. That decision should of course be respected. Even so, this question still plants a seed. I remember one occasion when someone I asked didn't want to talk about this matter. About a month later, they came to see me. "You remember that question you asked?" they said. I nodded. "Well, I'm ready to answer it now." I think I was one of the first people to whom they disclosed their sexual orientation.

If someone does disclose their LGBTI status, there are many other things which we should do. We should assure them of confidentiality unless they give us permission to disclose their status to anyone else. We should also discuss with them whether there is anyone else who should be told, and how this might be done. We should ask whether there are special people in their life who are really their family of choice, and who would be the most appropriate person to be their substitute decision maker. We should also ask them to speak to us if anything is said or done which is hurtful to them as an LGBTI person, and we should tell them about the mechanism to receive and resolve complaints. We should also ask if we can check in with them from time to time just to see how they're going.

### **Staff education and training**

There are external agencies which provide LGBTI training. Rightly or wrongly, some Catholic organisations have concerns that training delivered by external agencies might not respect Catholic ethical standards. One way forward is to send two relatively senior staff to external LGBTI training, and then to have these staff deliver your organisation's internal training. This commitment of our own staff demonstrates an organisation's commitment to diversity training. The involvement of our own staff also promises to ensure that our diversity training will be both ongoing and responsive to the particular needs of our organisation.

Education and training about LGBTI issues is important for all staff. Many aged care workers come from culturally and linguistically diverse (CALD) backgrounds. In some cases, we may have to challenge some of the cultural

messages, attitudes and behaviours which they have learnt about LGBTI persons.

Education and training should help staff to understand what words, behaviours and attitudes are not acceptable because they are homophobic or transphobic. It should help them to identify what words, behaviours and attitudes are acceptable and expected. It should also advise them who they should speak to if they have questions about what they should say or do themselves, or if they have concerns about the words, behaviours and attitudes of others.

### **Mechanism to receive and resolve complaints**

Some mechanism to receive and resolve complaints is needed, and it should be clearly set out in an organisation's policy and procedures. The aim should be not for a punitive mechanism, but for a light touch which can still effectively resolve concerns. Mistakes probably will be made. We should accept this. But mistakes must be faced and resolved.

At the same time, it must be made clear that serious or ongoing issues could result in the discipline of staff or even dismissal from employment.

### **Pope Francis and Diego Neria Lejárraga**

Let us conclude with a story. It is a story which perhaps more clearly than any other way expresses what this is all about. It is the story of Pope Francis and Diego Neria Lejárraga:

Diego is Spanish. He is 48 years old. He is a practising Catholic. And Diego was born a woman – or assigned female at birth, as they now say. He was also transgender, and for many years endured what he called living in "a body what felt like a prison that absolutely didn't correspond with what my soul felt."<sup>28</sup> Diego didn't do anything about this until after his mother died. But a year after his mother's death, when he was 40, Diego began to transition to male.<sup>29</sup> He finally had surgery mid-2014. What exactly was done, we do not know. Nor do we need to know.

....Diego wrote to Pope Francis. He asked a very sad question. He asked whether there was a place in the church for someone like him....

Diego reports that his bishop was always supportive and very good to him. However, the local parish priest called him "the daughter of the devil." And parishioners said that after having had this surgery, he shouldn't go to Communion any more. Indeed, as a result, Diego was afraid to receive Communion.<sup>30</sup>

Diego wrote to Pope Francis. He asked a very sad question. He asked whether there was a place in the church for someone like him.

In the Catholic calendar, December 8 is the feast of the Immaculate Conception. It is obviously a special day for Pope Francis, for he has decreed that on 8 December 2015, the Extraordinary Year of Mercy will begin. On 8 December 2014, Pope Francis gave us a parable of mercy.

On that day, Diego's phone rang. "Soy el Papa Francesco," the voice said in Spanish – "I am Pope Francis." They talked for quite a long time. Indeed, in the early stages, it was mostly Diego who spoke. And it was the pope who listened. But eventually Pope Francis did speak. This is what he said: "God loves all his children, however they are; you are a son of God, who accepts you exactly as you are. Of course you are a son of the Church!"<sup>31</sup> Note that when he spoke to Diego, Francis used the preferred gender.

....Pope Francis has given us an example of how Catholics should respond to people who are LGBTI....

Pope Francis learnt that Diego was engaged to be married. His fiancée is an attractive woman of about the same age whose name is Macarena. Francis wanted to meet both of them. He phoned back again to arrange this on 20 December, and they agreed to meet at 5 pm on Saturday 24 January 2015. Pope Francis suggested that they meet on the weekend so that Diego didn't have to take time off work. He also said, "If you have no money, when you're here I'll give you an envelope to cover your expenses." Pope Francis arranged to meet them not at his office but at his private quarters at the Santa Marta guesthouse. "When you get here," he said, "tell the Swiss Guards you have a meeting with me, and that's it."<sup>32</sup>

Pope Francis embraced Diego.<sup>33</sup> Diego will not discuss the meeting itself, insisting that it was private.<sup>34</sup> He did say, "The meeting was a wonderful, intimate, unique experience that changed my life. Now I am finally at peace."<sup>35</sup>

Well, that's what it's all about. Pope Francis has given us an example of how Catholics should respond to people who are LGBTI. What is suggested in this article is to try to ensure that in every Catholic aged care home we will be able to do what the pope has already done.

## ENDNOTES

<sup>1</sup> See, for example, John XXIII, *Mater et Magistra (Christianity and Social Progress)*, #236, Holy See, [http://w2.vatican.va/content/john-xxiii/en/encyclicals/documents/hf\\_j-xxiii\\_enc\\_15051961\\_mater.html](http://w2.vatican.va/content/john-xxiii/en/encyclicals/documents/hf_j-xxiii_enc_15051961_mater.html); and Paul VI, *Octogesima Adveniens (A Call to Action)*, #4, Holy See, [http://w2.vatican.va/content/paul-vi/en/apost\\_letters/documents/hf\\_p-vi\\_apl\\_19710514\\_octogesima-adveniens.html](http://w2.vatican.va/content/paul-vi/en/apost_letters/documents/hf_p-vi_apl_19710514_octogesima-adveniens.html).

<sup>2</sup> Most of this material on transgender people is summarised from Department of Health and Ageing, Australian Government, *National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy*, 18–19, 2012, Department of Social Services, [https://www.dss.gov.au/sites/default/files/documents/08\\_2014/national\\_ageing\\_and\\_aged\\_care\\_strategy\\_lgbti\\_print\\_version.pdf](https://www.dss.gov.au/sites/default/files/documents/08_2014/national_ageing_and_aged_care_strategy_lgbti_print_version.pdf).

<sup>3</sup> Australian Human Rights Commission (AHRC), *Resilient Individuals: Sexual Orientation, Gender Identity & Intersex Rights*, 5, 2015, AHRC, [https://www.humanrights.gov.au/sites/default/files/document/publication/SOGII%20Rights%20Report%202015\\_Web\\_Version.pdf](https://www.humanrights.gov.au/sites/default/files/document/publication/SOGII%20Rights%20Report%202015_Web_Version.pdf).

<sup>4</sup> William Leonard et al., *Private Lives 2: The second national survey of the health and wellbeing of GLBT Australians*, 2012, Gay and Lesbian Health Victoria (GLHV), <http://www.glhv.org.au/files/PrivateLives2Report.pdf>; William Leonard, Anthony Lyons, and Emily Bariola, *A Closer Look at Private Lives 2: Addressing the mental health and wellbeing of lesbian, gay, bisexual and transgender (LGBT) Australians*, April 2015, GLHV, [http://www.glhv.org.au/files/Closer\\_Look\\_Private\\_Lives2.pdf](http://www.glhv.org.au/files/Closer_Look_Private_Lives2.pdf).

<sup>5</sup> It was therefore a self-selected survey rather than a random one. While this may have introduced some bias, its authors argue that this online survey was still an effective way of gathering information about a hard to access and 'hidden' population like GLBT people. For this, see *Private Lives 2*, 5.

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<sup>9</sup> Catherine Barrett, *My People: A project exploring the experiences of Gay, Lesbian, Bisexual, Transgender and Intersex seniors in aged-care services*, June 2008, Matrix Guild Victoria (MGV), [http://www.matrixguildvic.org.au/docs/MyPeople\\_Exploring-Experiences-2008.pdf](http://www.matrixguildvic.org.au/docs/MyPeople_Exploring-Experiences-2008.pdf); Catherine Barrett, Jo Harrison, and Jane Kent, *Permission to Speak: Determining strategies towards the development of gay, lesbian, bisexual, transgender and intersex friendly aged care services in Victoria*, April 2009, MGV, [http://www.matrixguildvic.org.au/docs/MyPeople\\_Permission-To-Speak-2009.pdf](http://www.matrixguildvic.org.au/docs/MyPeople_Permission-To-Speak-2009.pdf); Catherine Barrett, *We Live Here Too: A guide to lesbian inclusive practice in aged care*, April 2011, MGV, <http://www.matrixguildvic.org.au/publications.htm>; Catherine Barrett and Carolyn Whyte, *Creating lesbian, gay, bisexual, transgender and intersex (LGBTI) inclusive Residential Aged Care Services (The RAC Pack)*, 2013, Val's Café, [http://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEWjG\\_J-q9LLJAhXhJaYKHytCbEQfggcMAA&url=http%3A%2F%2Fwww.valscafe.org.au%2Findex.php%2Fresources%2Fitem%2Fdownload%2F19\\_4604865b5c43f9e4c6488aa8cfe857b&usq=AFQjCNH5n7-VkWC9fNV2q7j6Oiuk1LzByg&bv=bv.108194040.d.dGY](http://www.google.com.au/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEWjG_J-q9LLJAhXhJaYKHytCbEQfggcMAA&url=http%3A%2F%2Fwww.valscafe.org.au%2Findex.php%2Fresources%2Fitem%2Fdownload%2F19_4604865b5c43f9e4c6488aa8cfe857b&usq=AFQjCNH5n7-VkWC9fNV2q7j6Oiuk1LzByg&bv=bv.108194040.d.dGY); Catherine Barrett, Carolyn Whyte, and Pauline Cramer, *Creating LGBTI Inclusive Home and Community Care Services (The HACC Pack)*, 2014, Val's Café, <http://www.valscafe.org.au/index.php/resources/item/106-hacc-pack>; *Self-assessment and planning (SAP) tool for LGBTI inclusive aged care*, 2014, Val's Café, <http://www.valscafe.org.au/index.php/resources/item/108-sap-tool>; Catherine Barrett et al., *No need to straighten up: Discrimination, depression, anxiety and older lesbian, gay, bisexual, transgender and intersex Australians*, July 2014, beyondblue, <https://www.beyondblue.org.au/docs/default-source/research-project-files/bw0263-no-need-to-straighten-up---full-report---pdf.pdf?sfvrsn=2>; Catherine Barrett, *We Are Still Gay: an evidence based guide to inclusive services for lesbian, gay, bisexual and trans people living with dementia*, 2015, <http://valscafe.org.au/index.php/resources/item/131-we-are-still-gay-an-evidence-based-guide-to-inclusive-services-for-lesbian-gay-bisexual-and-trans-people-living-with-dementia>.

<sup>10</sup> This includes articles by Anthony Brown, Carrie Hayter, and Catherine Barrett; Noel Tovey; Rebecca Reynolds, Samantha Edmonds, and Y. Gavriel Ansara; Helen Waite; Y. Gavriel Ansara; J. R. Latham and Catherine Barrett; Pauline Cramer et al.; Melanie Dicks, Evelyn Santoro, and Steve Teulan; Stephen Neville, Bernie Kushner, and Jeffrey Adams; Catherine Barrett et al.; and Mark Hughes and Colleen Cartwright. For these articles, see *Australasian Journal of Ageing*, 34, Supplement 2 (October 2015), online at <http://onlinelibrary.wiley.com/doi/10.1111/ajag.2015.34.issue-s2/issuetoc;jsessionid=B040534FAB8299A5B524D4679C14081F.f02t02>.

<sup>11</sup> See, for example, *No need to straighten up*, 6–7.

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<sup>13</sup> Department of Social Services, Australian Government, "Eligibility for diverse needs," My Aged Care, <http://www.myagedcare.gov.au/eligibility-and-assessment/eligibility-diverse-needs>.

<sup>14</sup> *National LGBTI Ageing and Aged Care Strategy*, 3.

<sup>15</sup> All these documents are available from the website of the Holy See: Congregation for the Doctrine of the Faith (CDF), *Declaration on Certain Questions Concerning Sexual Ethics (Persona Humana)*, 29 December 1975, Holy See, [http://www.vatican.va/roman\\_curia/congregations/cfaith/documents/rc\\_con\\_cfaith\\_doc\\_19751229\\_persona-humana\\_](http://www.vatican.va/roman_curia/congregations/cfaith/documents/rc_con_cfaith_doc_19751229_persona-humana_)



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<sup>16</sup> Catholic Health Australia (CHA), *Code of Ethical Standards for Catholic Health and Aged Care Services in Australia*, Part II, Section 3.11, CHA, <http://www.cha.org.au/images/resources/Code%20of%20ethics-full%20copy.pdf>.

<sup>17</sup> *Letter on the Pastoral Care of Homosexual Persons*, #7.

<sup>18</sup> *Considerations Regarding Proposals to Give Legal Recognition to Unions between Homosexual Persons*, #11.

<sup>19</sup> *Letter on the Pastoral Care of Homosexual Persons*, #3.

<sup>20</sup> *Declaration on Certain Questions Concerning Sexual Ethics*, #8.

<sup>21</sup> *Letter on the Pastoral Care of Homosexual Persons*, #3.

<sup>22</sup> *Some Considerations Concerning Non-Discrimination*, #12.

<sup>23</sup> *Letter on the Pastoral Care of Homosexual Persons*, #10. <sup>24</sup> *Ibid.*, #2.

<sup>25</sup> As well as the *National LGBTI Ageing and Aged Care Strategy*, there is also Department of Social Services (DSS), Australian Government, *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds*, 20 December 2012, <https://www.dss.gov.au/ageing-and-aged-care/older-people-their-families-and-carers/people-from-diverse-backgrounds/national-ageing-and-aged-care-strategy-for-people-from-culturally-and-linguistically-diverse-cald-backgrounds>. Other resources also exist, including a soon-to-be-released Information Package *Caring for Forgotten Australians, Former Child Migrants and Stolen Generations*. For these, see DSS, "People from diverse backgrounds," <https://www.dss.gov.au/our-responsibilities/ageing-and-aged-care/older-people-their-families-and-carers/people-from-diverse-backgrounds>.

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<sup>27</sup> See, for example, the story of Michael Rogers in Rick Morton, "Elderly learning to embrace life burdened by secrets of sexuality," 29 October 2015, *The Australian*, <http://www.theaustralian.com.au/news/health-science/elderly-learning-to-embrace-life-burdened-by-secrets-of-sexuality/story-e6frg8y6-1227586026324?sv=7becb11cac3748375d2085781c4eebad>.

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<sup>30</sup> Hilary White, "Pope receives 'transgender' woman and female partner for private audience," 28 January 2015, *LifeSite News*, <https://www.lifesitenews.com/news/pope-receives-transgender-woman-and-female-partner-for-private-audience>.

<sup>31</sup> Austen Ivereigh, "'Of course you are a son of the Church', Francis tells transgender man," *Catholic Voices Comment*, <http://cvcomment.org/2015/01/28/of-course-you-are-a-son-of-the-church-francis-tells-transgendered-man/>.

<sup>32</sup> *Ibid.*

<sup>33</sup> Roberts, "Pope receives transgendered man."

<sup>34</sup> Ivereigh, "Of course you are a son of the Church."

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All online material accessed 30 November 2015.

Kevin McGovern ✉

# Older Persons in Australia: Secular and Catholic Perspectives

*Negative portrayals of older persons in Australian culture have led to ageist attitudes and behaviours towards them. For the older person, this can result in self-deprecation, which in turn leads to poorer health, diminished wellbeing, and reduced mental ability. It can also negatively affect an older person's motivation to be an active member of society, resulting in a sense of isolation. Ageism also disregards the positive economic and social contributions that older persons make to the wider community. Drawing on both secular and Catholic viewpoints, this article seeks to recognise, challenge, and move to overcome ageism and age discrimination in Australia.*

It is difficult to define when a person should be classified as being 'old'. The term 'older person' has been used to describe someone who is 65 years or older – a number which was chosen probably because this has been seen as retirement age when many people experience a change in their social role.<sup>1</sup> Advances in healthcare have raised the level of health, wellbeing and subsequent longevity of older persons, leading to a growing aged population worldwide. In Australia, in 1960–1962, men were expected to live for 67.9 years, and women for 74.2 years. In 2011–2013, the life-expectancy had increased to 80.1 years for men, and 84.3 years for women.<sup>2</sup> According to the Australian Bureau of Statistics, in June 2014 older persons aged 65 and over made up 14.7% of the Australian population.<sup>3</sup> This proportion is expected to more than double by the year 2055.<sup>4</sup>

With this demographic change, and coinciding with the views of other governments around the world,<sup>5</sup> the Australian government has expressed economic concerns, often claiming that the demand for services (including welfare) from the ageing community will far outweigh the tax revenue from working-age persons.<sup>6</sup> This economic concern has often been described as "catastrophic" and burdensome.<sup>7</sup> Such portrayal of older persons as an economic burden to Australian society may lead to ageism and stigmatisation.

## Negative attitudes towards the older person

Ageism can be defined as "a set of social relations that discriminate against older persons and set them apart as being different."<sup>8</sup> This may lead to the stigmatisation of older persons. Older persons are also often stereotyped as being dependent, frail and incompetent.<sup>9</sup> These negative attributes and the stigmatisation of older persons can influence people's attitudes, decisions and actions. Often, these attitudes stem from, and are shaped by: interactions with older persons from an early age (including family relationships),<sup>10</sup> a general lack of understanding of the ageing process,<sup>11</sup> and the reinforcement of negative portrayals of older persons by

such sources as the mass media.<sup>12</sup> For the older person, these ongoing negative attitudes about ageing can result in self-deprecation, which in turn leads to poorer health, diminished wellbeing and reduced mental ability.<sup>13</sup> These ageist attitudes may also negatively affect an older person's motivation to be an active member of society, resulting in a sense of isolation.<sup>14</sup>

Isolation and segregation of the older person is evident in the community with the establishment of retirement villages and residential aged care homes. Whilst these facilities aim to cater to the needs of the older person, Petersen and Warburton argue that the negative stereotypes such as dependency attributed to older persons in some such environments, influence government policy and business practice.<sup>15</sup> This in turn may result in the planning of these spaces away from the wider community. In addition, Hagestad and Uhlenberg suggest that the age-segregated housing of older persons reduces intergenerational interactions and perpetuates ageist stereotypes.<sup>16</sup>

....For the older person, these ongoing negative attitudes about ageing can result in self-deprecation, which in turn leads to poorer health, diminished wellbeing and reduced mental ability. These ageist attitudes may also negatively affect an older person's motivation to be an active member of society, resulting in a sense of isolation....

Ageist stereotyping can also impact upon an older person's ability to engage and interact with other members of the community. This can be particularly troubling when an older person requires healthcare, and interacts with health professionals who lack experience in working with older persons. Studies have shown that negative attitudes held by some nurses and other health professionals impact upon their ability to provide quality healthcare.<sup>17</sup> Nussbaum and colleagues suggest that this may be related to the stereotype which assumes that all older persons are dependent and frail.<sup>18</sup> This misconception of older persons often does not take into account the difference between those who are healthy, independent and do not require constant medical attention, and those who have chronic conditions with complex healthcare needs.<sup>19</sup>

A report by the Australian Human Rights Commission found that a large proportion of Australians – 71% – feel that age discrimination is common.<sup>20</sup> Additionally, it states that 43% of Australians aged 65 and over have experienced some sort of discrimination because of their age.<sup>21</sup> The report also identifies that discrimination exists against older workers, mainly due to negative attitudes associated with competence and the ability to learn new skills. Western societies such as Australia often focus on

the productivity of their people, placing their value and worth on the financial contributions they make through paid employment.<sup>22</sup> This perspective impacts upon an individual's self-esteem and sense of belonging in society. Older persons who are not involved in the active workforce and those who are discriminated against due to their age, may feel segregated from society. This may in turn lead to negative mental health outcomes for them, and further demands on the health and welfare systems.

Where traditionally the older person was greatly respected because of their age and life experience, social and familial structural changes over time have shifted this concept, placing a greater importance of what a person can *do* rather than who they *are*. This view reduces the inherent value and worth of a person – especially older persons who are no longer part of the active workforce and who do not feel that they are contributing to society. This position also fails to acknowledge the positive social and economic contributions that older persons make which are not tied to paid employment.

### **Positive contributions by older persons in society**

Older persons make both social and economic contributions to their communities which often go unnoticed by the wider community. It is important to highlight these contributions so that older persons are recognised by society as valuable members and not simply considered a burden. A primary activity steered by older persons, providing social and economic benefit, is volunteer work. This is significant in Australia as a large proportion of older Australians are volunteers, providing invaluable support to many organisations.<sup>23</sup> In 2010, 2.9 million Australians over 65 years were involved in volunteer work.<sup>24</sup>

Volunteer work includes various activities which assist family, friends and the community. Household duties, childcare, fundraising as well as participation in governance and citizenship groups are some examples of these activities. The contributions of volunteers add value to services which assist individuals and enhance a sense of community spirit.<sup>25</sup> This is of particular importance in remote Indigenous communities with older Indigenous Australians.<sup>26</sup> Their contributions in providing social support and imparting cultural wisdom to the younger generation is highly regarded, respected and valued.<sup>27</sup> Not only does volunteerism benefit communities, but the act of volunteering has been shown to improve the psychological wellbeing of the older person, adding a sense of purpose to life and a sense of belonging to a social group.<sup>28</sup>

Contrary to the view that older persons are in need of care, it is often the older person who is caring for others. They are often informal carers to their spouse, grandchildren or other loved ones who may not be able to care for themselves.<sup>29</sup> Visitation of fellow older persons who are socially isolated is also a significant contribution which they make towards improving interconnectedness within communities.<sup>30</sup> Such activities mutually reduce isolation, and promote mental health and wellbeing.

These social benefits are defined in the literature as social capital, that is, “the array of social contacts that give access to social, emotional and practical support” within communities.<sup>31</sup>

It has been estimated that Australians aged over 65 contribute almost \$39 billion dollars per year to the Australian economy through their unpaid caring and volunteer work.<sup>32</sup> Additionally, intergenerational transfers of money and property from older persons to younger members of the family have been estimated to be billions of dollars.<sup>33</sup> It has also been recognised that the financial contributions of older persons to charitable organisations is significant.<sup>34</sup> It can be concluded that many older persons today are still ‘productive,’ financially contributing to society as well as continuing to build and shape it.

### Catholic Social Teaching

Catholic Social Teaching is the body of doctrine which helps shape the Catholic sense of social justice.<sup>35</sup> Recognition of and respect for the human person is the foundation of this teaching. This in turn arises from the Catholic belief that all persons are created in the image and likeness of God. Significantly, if our value depends ultimately on the fact that we are made in the image of God, our inherent value or worth cannot be diminished because of age. It is also not confined to the ability to *do* (which may be limited in older persons who have declined physically and/or cognitively), but rather depends on *who* a person is: that is, a human *being*.

....Pope Francis has affirmed that “a society truly welcomes life when it recognizes that it is also precious in old age”....

Catholic Social Teaching includes a profound recognition that human beings are social beings. This helps Catholics to recognise the paramount importance of social inclusion. Further, Catholic principles such as subsidiarity and solidarity also promote a sense of intergenerational networking and kinship.<sup>36</sup> Subsidiarity requires that we consult with older persons when we seek to assist them so as to ensure that what we do respects their independence and self-determination. Much like the positive contributions that volunteerism provides, solidarity encourages interconnectedness between and within communities, promoting the common good within God’s family.<sup>37</sup>

Papal teaching also highlights the Catholic perspective about older persons. St Pope John Paul II’s *Letter to the Elderly* in the International Year of the Older Person (1999) painted a vivid picture as to how we should relate to the older person.<sup>38</sup> Being an older person himself when he wrote this, he recognised the positive contributions that an older person can make to society, including the

imparting of wisdom and the maturity gained through life experience. Pope Benedict XVI reaffirmed these views, and also insisted that longevity should be viewed as a blessing from God.<sup>39</sup> In his own teaching about the elderly, Pope Francis has recognised and opposed the “throw away culture” that society sadly often adopts in its dealings with older persons.<sup>40</sup> He has affirmed that older persons have inherent value, and that “a society truly welcomes life when it recognizes that it is also precious in old age.”<sup>41</sup>

The See, Judge, Act<sup>42</sup> process for social justice provides a framework which can assist in applying these principles of Catholic Social Teaching. It provides steps for practical action to change a situation so as to remedy social injustice. In the context of older persons, we can identify that older persons are marginalised in society (See); analyse the factors which cause this marginalisation, reflect on these in the light of Catholic Social Teaching, and discern possible actions (Judge); and then Act, that is, plan and take action to transform the social structures and reduce the marginalisation of older persons.

### Conclusion

As the numbers of older persons in Australian society continue to grow, issues related to older persons take on increasing importance. Negative stereotyping has resulted in some exclusion of older persons from various activities, including their involvement in the workforce. Furthermore, negative stereotyping may also have impacted upon older persons’ psychological wellbeing, their social standing, and the quality of health care they receive.

Whilst it is recognised in the literature that older Australians do contribute socially and economically, ageist attitudes which ignore this significant contribution are still a part of the Australian cultural psyche. Educating individuals about ageist attitudes and demystifying the ageing process can help reduce age-related stereotyping. Additionally, focusing on the older person as a human being deserving of respect and dignity, enhances their wellbeing. This in turn helps them contribute to society in other ways and gives them a continued sense of purpose in life.

### ENDNOTES

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<sup>5</sup> Kevin Andrews, “How the Australian Government views its responsibilities in an ageing world,” *Australasian Journal on Ageing* 24 (2005): S2–S4 at S2.

<sup>6</sup> *Intergenerational Report*, 1. See also AIHW, *Australia’s welfare 2013*, Australia’s welfare series no.11, cat. no. AUS 174 (Canberra: AIHW,

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<sup>7</sup> David de Vaus, Matthew Gray, and David Stanton, *Measuring the value of unpaid household, caring and voluntary work of older Australians* (Melbourne: Australian Institute of Family Studies, 2003), 6.

<sup>8</sup> Victor Minichiello, Jan Browne, and Hal Kendig, "Perceptions and consequences of ageism: views of older people," *Ageing and Society* 20 (2000): 253–278 at 253.

<sup>9</sup> Mary Kite et al., "Attitudes Toward Younger and Older Adults: an Updated Meta-Analytic Review," *Journal of Social Issues* 61, no. 2 (2005): 241–266 at 245.

<sup>10</sup> Becca Levy, "Mind Matters: Cognitive and Physical Effects of Ageing Self-Stereotypes," *Journal of Gerontology Series B: Psychological Sciences and Social Sciences* 58, no.4 (2003): 203–211 at 203.

<sup>11</sup> Minichiello, Browne, and Kendig, 254.

<sup>12</sup> Australian Human Rights Commission (AHRC), *Fact or fiction? Stereotypes of older Australians* (Sydney: AHRC, 2013), 9, [https://www.humanrights.gov.au/sites/default/files/document/publication/Fact%20or%20Fiction\\_2013\\_WebVersion\\_FINAL\\_0.pdf](https://www.humanrights.gov.au/sites/default/files/document/publication/Fact%20or%20Fiction_2013_WebVersion_FINAL_0.pdf).

<sup>13</sup> Jennifer Richeson and Nicole Shelton, "A Social and Psychological Perspective on the Stigmatization of Older Adults," in *When I'm 64*, ed. Laura Carstensen and Christine Hartel (Washington: The National Academies Press, 2006), 190.

<sup>14</sup> Jon Nussbaum et al., "Ageism and Ageist Language Across the Life Span: Intimate Relationships and Non-Intimate Interactions," *Journal of Social Issues*, 61 no. 2 (2005): 287–305 at 294.

<sup>15</sup> Maree Petersen and Jeni Warburton, "Residential complexes in Queensland, Australia: a space of segregation and ageism?" *Ageing and Society* 32 (2012): 60–84 at 60.

<sup>16</sup> Gunhild Hagestad and Peter Uhlenberg, "The Social Separation of Old and Young: A Root of Ageism," *Journal of Social Issues* 61, no.2 (2005): 343–360 at 348.

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<sup>18</sup> Nussbaum et al., 295–296.

<sup>19</sup> John McCormack, "Acute hospitals and older people in Australia," *Ageing and Society* 22, no. 5 (2002): 637–646 at 641.

<sup>20</sup> *Fact or Fiction?*, 4.

<sup>21</sup> *Ibid.*, 9.

<sup>22</sup> *Intergenerational Report*, 1. See also Nussbaum et al., 294.

<sup>23</sup> AIHW, *Older Australians at a glance*, 4<sup>th</sup> ed., cat. no. AGE 52, (Canberra: AIHW, 2007), 28.

<sup>24</sup> Volunteering Australia, *State of Volunteering in Australia*, (2012), <http://www.volunteeringaustralia.org/wp-content/uploads/State-of-Volunteering-in-Australia-2012.pdf>.

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<sup>37</sup> *Ibid.* Solidarity can be defined as "a firm and persevering determination to commit oneself to the common good; that is to say, to the good of all and of each individual, because we are really responsible for all."

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All online material accessed 21 May 2015.

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## Dignity Therapy in End-of-life Care

*Dignity Therapy provides patients with a terminal illness the opportunity to share their life experiences. Their life narrative is reflected upon, shared, transcribed, and later bequeathed to their family and friends. The generativity document produced as a result of Dignity Therapy is a declaration and a lasting legacy, a manuscript that holds meaning and makes meaning at a point in life when people may feel a sense of despair and loss. This article will follow the development of Dignity Therapy, and why it should be acknowledged as an integral aspect of end-of-life care for patients, their families and friends, and healthcare professionals.*

Dignity therapy is a brief psychotherapeutic intervention employed predominately in palliative care to respond to psychosocial and existential distress experienced by terminally ill patients.<sup>1</sup> It was initially used with cancer patients. Now it is also used with residents in aged care facilities, and patients with chronic and mental illness. End-of-life care provides not just physiological comfort but must encompass care relating to the patient's social and cultural identity, and spirituality. The individual's social and cultural identity is affirmed by the interactions they share with family and wider community networks. It

also relates to the way that patients will make decisions at the end-of-life. The way each person decides and experiences end-of-life is unique. Some patients may struggle, whilst others will adapt to the frequent changes that happen at the end-of-life, till they breathe their last. However this experience is encountered, it is also usually a time for deep reflection, and a chance to strengthen personal relationships. Therefore, granting patients the opportunity to share their stories and leave behind a legacy for their family is valuable, and also a profoundly enriching experience for everyone involved. Dignity Therapy facilitates this endeavour by having trained healthcare professionals produce a written account of the patient's story. This article traces the history of Dignity Therapy from its beginning and details how it has emerged as a valuable resource in end-of-life care.

### **The meaning of human dignity**

The term 'dignity' is common in medicine but also frequently appears in human rights discourse. The Australian Catholic *Code of Ethical Standards* states that "our care for people who are sick, aged or disabled is founded on love and respect for the inherent dignity of every human being."<sup>2</sup> Where medicine and clinical practice are concerned, the concept of dignity is central to patient-centred care. One straightforward implication is that patients' needs should direct the course of clinical practice and care. At the same time, this foundational concept can raise inherent challenges: how, for example, can we best guard patient dignity as we consider clinical pathologies and diagnoses? Making provisions to protect, respect and fulfil patient dignity can indeed be quite challenging. A patient's experience of illness is multifaceted, and set in a dynamic social and cultural environment. This is transformed further in hospital or hospice care.<sup>3</sup> A real danger is that dignity can become mere rhetoric as care providers meet enormous demands and finite resources are stretched—in these cases, dignity can become a "casualty of care."<sup>4</sup> Dignity is a poignant expression of, and inherent to, our identity. It contributes to our experiences and our interactions with others. In some cases, people may feel a loss of dignity at the end of life as they become increasingly dependent on other people. It was through the need to address this perceived loss of dignity in select patient groups that Dignity Therapy was first developed, and since then has made remarkable progress for many patients and the families.

### **Dr Harvey Max Chochinov and Dignity Therapy**

Dr Chochinov is recognised as the pioneer of Dignity Therapy who first described the Dignity Model. He is a Professor of Psychiatry at the University of Manitoba in Canada and Director of the Manitoba Palliative Care Research Unit.<sup>5</sup> The research unit's website notes that patient dignity is influenced by the way in which patients see themselves through their interactions with their care provider: "[the care providers] are often the 'mirror' by which patients and their families judge their own status within the system."<sup>6</sup> Because of this, the interaction between healthcare provider and patient is an underlying

theme in Chochinov's work in this area. Writing in *Social Science and Medicine* in 2002, Chochinov and colleagues<sup>7</sup> provided a glimpse of the lived experiences of terminally ill patients and specifically their understanding of 'dignity'. Qualitative methodologies were employed whereby semi-structured interviews were analysed using constant comparative methods. Three major categories were identified – illness-related concerns, dignity conserving repertoire, and social dignity inventory – as well as various themes and subthemes. Broadly, these findings were used to develop the Dignity Model. This model showed that dignity in terminal illness is facilitated by internal aspects such as illness-related concerns, and external aspects such as environment and social context. These can help support a patient's dignity by providing direction to health professionals caring for these patients particularly as they near death. Some examples of dignity conserving practice are involving patients in decision-making about their care, maintaining their familiar routines, and enabling patients to contribute to something that will serve as a lasting legacy.<sup>8</sup>

Dignity therapy is a brief psychotherapeutic intervention employed predominately in palliative care to respond to psychosocial and existential distress experienced by terminally ill patients. Now it is also used with residents in aged care facilities, and patients with chronic and mental illness.

In a separate study published in the same year, Chochinov led a research team that sought to demonstrate the relationship between dignity and the willingness to live. Here he used a cross-sectional cohort study design inviting participation from two palliative care units.<sup>9</sup> Participants were those given a life expectancy of six months, and eligibility was determined by the care staff in the unit. Participants were required to complete various questionnaires that rated their sense of dignity and quality of life, and others including the McGill pain questionnaire and measures of functional dependency. The researchers were interested in which patients reported a loss of dignity, and how they differed from those who did not feel they had lost their dignity. The study cohort included 213 cancer patients in palliative care, living an average of 71 days following enrolment in the study. A significant proportion of patients reported having a strong sense of dignity regardless of duration or survival. The patients who reported a loss of dignity were often cared for in hospital and were younger. Cancer patients with a sense of intact dignity were less likely to report a wish to hasten death, feel depressed, hopeless or anxious. They were also able to attend to their own personal care like bathing, toileting and dressing. As expected, this group had a better quality of life. Statistical analysis showed a strong correlation between loss of dignity and changes in outward appearances, feelings of

being a burden and dependent on others, experiences of pain, and being in hospital.<sup>10</sup> In the discussion Chochinov says “a person’s sense of dignity is a particularly resilient construct and, in most instances, is able to withstand the various physical and psychological challenges that face patients who are terminally ill.”<sup>11</sup> Where previously there had been an assumption that terminal illness itself was a precursor to a loss of dignity, it may actually be that it is the experience of inpatient care that causes people to feel least resilient.<sup>12</sup> This finding was significant because it helps to justify the use of a therapeutic intervention for patients at the end-of-life in hospital or palliative care settings.

This research culminated into what is now referred to as Dignity Therapy—an intervention pioneered by Chochinov and his team to address issues related to loss of dignity at the end-of-life, most specifically in palliative care. Chochinov recognised that dignity is an important construct that should facilitate conversations around death and dying for the patient and their family.<sup>13</sup> He argued that the extent of despair and how health care professionals respond to patients’ needs was insufficiently addressed in practice. Dignity Therapy was developed as a unique approach to address these concerns. In this, patients are given the opportunity to leave a lasting legacy of their life’s story for their family and friends. Their life’s narrative is initially recorded through conversation and later transcribed into text—also referred to as a ‘generativity document.’ The first cases of Dignity Therapy were evaluated and reported on in the *Journal of Clinical Oncology*.<sup>14</sup> In this study, participants were recruited from hospitals and community-based palliative care services in Canada and Australia. An interview guide was based on themes from the Dignity Model, and administered by a psychiatrist, psychologist or palliative care nurse. Since this study sought to make an initial assessment of patients’ psychometric measures, several brief questionnaires were completed in preparation for the actual Dignity Therapy session. The administrator of the questionnaires asked questions to prompt discussion. The interview was not premeditated by the administrator, and the patient was in control. The audio-recorded interview was transcribed verbatim and later edited for clarity. Follow-up interviews were scheduled if there was any ambiguity. The generativity document was read aloud to the patient, which inevitably evoked emotion as the patient heard for the first time intimate details about their life, in the voice of someone else. If further editing was requested, it was completed at this meeting. If more substantial work needed to be done, then another follow-up meeting was arranged. Chochinov acknowledged the immediacy of the entire process, due to the limited time that some patients have to live, as an issue with Dignity Therapy. The generativity document was bequeathed to a person of the patient’s choosing. For the purpose of Chochinov’s study, a series of post-intervention surveys were also distributed to patients. Overall, there was resounding support for Dignity Therapy with 76% reporting that it heightened their sense of

dignity, made them more hopeful of their future, and gave meaning to the time they had remaining.

The generativity document contained messages of love, happy memories as well as stories about regret, but most importantly it gave resolution and clarity at a point when there had perhaps been uncertainty. The survey administered before and after Dignity Therapy showed improvement in psychometric measures relating to hopefulness, dignity and anxiety.<sup>15</sup> Family members also responded positively to receiving the generativity document.<sup>16</sup>

### Dignity Therapy in other settings of care

A number of studies have examined the feasibility, acceptability and potential effectiveness of Dignity Therapy to reduce distress in older persons in residential aged care. Aged care residents report lower levels of distress than people who are terminally ill, so there is less potential for reduction of distress. Many aged care residents have some level of cognitive impairment, and for this reason cannot themselves participate in Dignity Therapy. Also, quite an amount of time is needed to develop the generativity document as residents recall additional people and events they want to include. With these provisos, one study found that residents did feel that Dignity Therapy had helped them. Above all, they felt that it made their life more meaningful, and particularly that the generativity document had helped their families.<sup>17</sup> Another study found that cancer patients and aged care residents experience similar dignity-related concerns, suggesting that Dignity Therapy could be beneficial particularly for those who are most distressed.<sup>18</sup>

....Overall, there was resounding support for Dignity Therapy with 76% reporting that it heightened their sense of dignity, made them more hopeful of their future, and gave meaning to the time they had remaining....

When an aged care resident is cognitively impaired, one strategy is to involve a family member in Dignity Therapy to participate on behalf of their cognitively-impaired loved one. Aged care providers report that the generativity document changes their appreciation of an aged care resident, and could even help them in providing ongoing care to them.<sup>19</sup>

The foundational work for Dignity Therapy was undertaken with patients at the end of life in Western countries. When a similar study was undertaken involving patients in Japan with advanced cancer, the researchers reported many more patients refused to participate. They suggested that this was due to cultural differences. Japanese culture includes “unawareness of death” as one aspect of a good death, and many terminally ill cancer patients in Japan cope by denying their impending death.

For this reason, Dignity Therapy should not be routinely recommended for terminally ill Japanese people. It may, however, be beneficial for those who hope to leave a legacy.<sup>20</sup>

Yet another study assessed Dignity Therapy in a community-based hospice setting. Reporting on 27 participants from a hospice in San Diego in California, the study noted the most commonly discussed topics covered in these generativity documents. It considered the costs and the cost-effectiveness of implementing Dignity Therapy in a community care setting. It also noted the need for more research on the suitability of Dignity Therapy for ethnic and religious minorities.<sup>21</sup>

....Dignity Therapy – “the penicillin of palliative care” – is perhaps the metaphorical ‘antibiotic’ to address the challenges of end-of-life care....

Finally, case reports of patients with mental health issues such as depression<sup>22</sup> and schizoaffective disorders<sup>23</sup> have provided promising anecdotal evidence in support of Dignity Therapy in mental health care. For these patients, Dignity Therapy provided a helpful distraction from their illness, and allowed them to focus instead on family and positive relationships and other experiences in their life.

## Conclusion

Respecting personal dignity and caring for the most vulnerable in our community, is an important aspect of Catholic social teaching and Catholic health, aged and community care. Oftentimes, through the experience of illness people come to appreciate that life is fragile. The depth of raw emotion experienced on learning about a terminal diagnosis is profound both for the patient and for those around them. The sudden realisation that a loved one will no longer be physically present and instead will become a memory, adds to the depth of raw emotion in family and friends that can be evoked at this time. This transition may be eased by promoting a sense of dignity for the dying person in the form of encouraging them to leave behind a legacy. Dignity Therapy has a significant role in facilitating these conversations around the end-of-life, where patients have an opportunity to share their life story, and family and friends can receive that story as a permanent reminder. Healthcare providers also appreciate what they learn about their patients through this process. Therefore, Dignity Therapy should be acknowledged as an integral aspect of end-of-life care for patients, their families and friends, and healthcare professionals.

Dignity Therapy – “the penicillin of palliative care,”<sup>24</sup> as it is eloquently described by its founder – is perhaps the metaphorical ‘antibiotic’ to address the challenges of end-of-life care. A generativity document is developed using an interview style format that explores various facets of lived experiences, and which facilitates a person’s sharing

with their loved ones their innermost emotions and stories. These stories are bountiful in sincerity and love, but also in regret and apologies. They are a lasting memory for those left behind to remember a life they shared, through the words of the one who has passed away.

## ENDNOTES

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All online material accessed 11 May 2015.

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