

Caring and Giving Hope to Persons Living with Progressive Cognitive Impairments and Those Who Care for Them: Statement of the Fourth International Colloquium of the International Association of Catholic Bioethicists (IACB)

**Introduction: The Fourth IACB Colloquium
by William F. Sullivan and John Heng**

The Fourth International Colloquium of the IACB (International Association of Catholic Bioethicists) was held from July 12 to 16, 2009 at the Kardinal-Schulte-Haus near Cologne, Germany, and sponsored by a grant from the German Association of the Order of Malta. Forty-nine invited participants came from a total of twenty countries in Africa, Asia, Australia, Europe, North and South America to discuss ethical issues arising in the care of people living with Alzheimer's disease and other progressive cognitive impairments, and to collaborate on a consensus statement. The participants work in geriatrics, psychiatry, psychology, family medicine, nursing, pastoral care, history, philosophy, theology, clinical ethics, law, and health economics. Besides their clinical and educational work in this area, many participants were shaped by their experiences of having cared for family members with progressive cognitive impairments.

History

The IACB international colloquia are held once every two years and focus each time on a different topic in bioethics. Prior to Cologne, in 2009, past colloquia have been held in Toronto (2003), Melbourne (2005), and London (2007). Regional colloquia also have taken place in Paris (2008) and Toronto (2004 and 2006), as well as annually in Australia under the auspices of the Australian Association of Catholic Bioethicists. The bioethicists who met in Toronto in 2003 recommended the establishment of the IACB, which today has around 200 active members in forty countries. The IACB aims to promote discussions and collaborative research among Catholic bioethicists so as to advance the thinking of Catholics on emerging and unsettled questions in bioethics and to contribute to dialogue with all members of society. Since 2005, the IACB has been sponsored by national associations of the Order of Malta, whose 900-year-old mission of witnessing to the Catholic faith and serving the needy ("*tuitio fidei et obsequium pauperum*") is manifested in the work of the IACB. The associations of the Order, in turn, provide financial, moral and spiritual support, while ensuring the IACB's academic independence.

Process

With input from bioethicists associated with the IACB, the planning committee of the colloquium, consisting of Ursula Sottong and Christoph von Ritter of Germany, and William Sullivan and John Heng of Canada, proposed areas in the care of persons living with progressive cognitive impairments that require ethical reflection. Experts in these areas were asked to write background papers that participants could read prior to the colloquium. The papers identified key questions for discussion within each area, as well as a range of positions on these questions. Some of the papers dealt with issues in philosophy, ethics, and theology that the authors thought were fundamental to caring for persons with progressive cognitive impairments; others considered ethical and legal issues emerging in care practices and policies. Background papers were prepared by Monsignor Peter Schallenberg, a German moral theologian; Fr. Myles Sheehan, a geriatrician from the U.S.; Julian C. Hughes, a British consultant in old-age psychiatry who holds a doctorate in philosophy; Mette Lebech, a philosopher from Ireland; Christine Jamieson, a Canadian theologian; Jane Adolphe, a professor of

law from the U.S.; James McManus, a British psychologist and an expert in public health; Wilhelmina Hoffman, director of the Silviahemmet, a non-profit foundation established by the Queen of Sweden for educating professionals and delivering care to persons with Alzheimer's Disease and other cognitive impairments, and Carol Taylor, a nurse and director of the Center for Clinical Bioethics at Georgetown University Medical Center in the U.S. Albrecht von Boeselager of Germany and William Sullivan of Canada began the colloquium with addresses that provided a framework for the discussions. At the colloquium, some participants offered interventions on particular questions not covered in the background papers. These included Fr. Paul Chummar of Kenya; Fr. Ben Fanaye of Nigeria; Peter Gummere, Jos Welie, and Linda Scheirton of the U.S.; John Ozolins of Australia, and Fr. Wieslaw Reglinski of Switzerland.

The background papers and relevant interventions were discussed by the participants in small groups and in plenary sessions, which gave free rein to the emergence of questions and diverse opinions. The first draft of a consensus statement, synthesizing those discussions, was prepared by William Sullivan and John Heng, and discussed in a plenary session at the colloquium. An editorial committee, consisting of Fr. Norman Ford, Ray Campbell, and Bernadette Tobin of Australia; Jos Welie and Daniel P. Sulmasy of the U.S.; Neil Weir of the U.K.; Paulina Taboada of Chile, and Jaro Kotalik, William Sullivan, and John Heng of Canada, helped to incorporate feedback from the other participants during the colloquium. This committee also considered further suggestions that were received from participants following the colloquium and produced two subsequent versions of the consensus statement that were reviewed by all participants, who were asked for permission to attach their names to the final document.

Highlights of the Consensus Statement

The statement notes, with concern, that persons living with Alzheimer's disease and other progressive cognitive impairments are often poorly understood and little valued within health care systems and communities around the world, and thus their care is often inadequate and inappropriate. The statement also addresses the plight of family members and other caregivers of persons living with cognitive impairments who seldom receive the education and assistance that they require. Among their most pressing needs is guidance and support to address the ethical issues that they encounter in providing care.

Because it is not possible in a short statement to address all such issues, participants in the Cologne colloquium decided to focus on establishing an ethical framework to guide reflections on specific questions regarding the care of persons living with progressive cognitive impairments and their families. The Cologne statement concludes with practical recommendations on some issues as illustrations of the application of this framework.

Participants of the colloquium decided to express the foundational stances found in the Cologne statement in two ways, first, philosophically to engage the broadest possible audience, and then by specifying what considerations are added by Catholic teachings and theological reflection. Some opposing positions on these foundational stances were also identified and rejected. For example, the statement affirms the intrinsic dignity and worth of all human beings, including those living with progressive cognitive impairments. It rejects the positions that such impairments undermine a person's humanity, and that aging, disability, dependency on others, suffering, and death lack meaning. Thus the statement strongly endorses enhancing resources and care at the end of life as an alternative to euthanasia. It also questions criteria for distributing health care resources that focus exclusively on maximizing efficiency and profit, according to which persons with progressive cognitive impairments

rank poorly. An important conclusion of the statement is the need to promote environments in which persons living with progressive cognitive impairments and their families are valued and supported. Such solidarity extends beyond health care settings to the whole community.

The statement also stresses that decisions regarding the care of persons with progressive cognitive impairments must take into account each person's circumstances, capabilities and vulnerabilities, as well as the full range of his or her needs, including relational and spiritual ones. Part of what is required for this to be implemented is improving the education of health care professionals, patients and their families on progressive cognitive impairments, including training and the opportunity for consultations on ethics, spirituality, palliative care, and issues surrounding death and bereavement. In particular, the statement highlights the importance of teaching members of society the ethical distinction between euthanasia, which is always wrong, and addressing symptoms that may have the unintended effect of hastening death or forgoing medical interventions that are optional because they present little hope of likely benefit to the patient or result in harm or other burdens to the patient that are excessive relative to those benefits. The statement identifies advance care planning, supported and substitute decision making, as well as various practices surrounding terminal sedation as areas that require further ethical reflection and discussion.

Overall, while recognizing that the diseases and conditions underlying various progressive cognitive impairments lead to death, the statement places its emphasis on giving hope at every stage of this process, from the initial diagnosis to end-of-life care to preparation for dying. In the words of Dr. Julian Hughes, a participant in the Cologne colloquium, the emphasis of the statement is on helping persons with progressive cognitive impairments and their families to "live better, richer lives" in the midst of what often are challenging circumstances.

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STATEMENT

Caring and Giving Hope to Persons Living with Progressive Cognitive Impairments and Those Who Care for Them: Statement of the Fourth International Colloquium of the International Association of Catholic Bioethicists (IACB)

Progressive Cognitive Impairments

1. Issues relating to the care of persons living with progressive cognitive impairments are among the most pressing concerns of our times and require ethical guidance. *Progressive cognitive impairments* in this statement refers to decline in more than one area of a person's cognitive or intellectual functioning (e.g., spatial orientation, short- and long-term memory, problem solving, judgment, decision making, speech and language) that becomes more severe over time, cannot be reversed, and eventually leads to death.¹ Changes in the person's behaviour (e.g.,

¹ The participants in this colloquium used the term *progressive cognitive impairments* rather than *dementia* for several reasons. First, we wanted to avoid the pejorative sense that *dementia* has acquired in many languages and the hopelessness that this term often conveys to diagnosed individuals and their caregivers. See V. Hachinski, "Shifts in Thinking About Dementia," *JAMA* 300.18 (Nov. 12, 2008): 2172-73; Don I. Trachtenberg and John Q. Trojanowski, "Dementia: A Word to Be Forgotten," *Archives of Neurology* 65.5 (May 2008): 593-95. Second, by using the plural *impairments*, we wanted to signal that the conditions we were discussing involve more than one area of cognitive functioning. Third, we wanted to focus only on those cognitive impairments that decline progressively, are irreversible, and lead to death. See U. Guehne, S. Riedel-Heller, and

agitation, aggression, disinhibition) and psychological symptoms (e.g., anxiety, depression, social withdrawal, apathy, irritability, delusions, hallucinations) are also common and may distress the person and his or her caregivers.² Progressive cognitive impairments are caused by disorders of the human brain, for instance, Alzheimer's disease, vascular dementia, dementia with Lewy bodies, and fronto-temporal lobe dementias. These disorders are more likely to develop with advancing age.³ There is currently no cure for these disorders but the decline in a person's cognitive functions may sometimes be slowed down, and the person may often be helped in other ways, through appropriate medication, assistance in tasks, psychosocial therapies and other means. From diagnosis to death, the remaining life span of persons living with progressive cognitive impairments varies according to the specific cause of the impairments and individual factors, but can be five or more years.⁴ Globally the number of persons living with progressive cognitive impairments is projected to rise as life expectancy increases, doubling every twenty years from 24.3 million persons in 2001 to 81.1 million in 2040. Most persons with progressive cognitive impairments (60%) now live in developing countries, and this proportion will grow to 71% by 2040.⁵

2. Persons living with progressive cognitive impairments depend in various ways on their families and others. Giving care is a labor of love that can bring joy to caregivers but also various challenges, including grappling with difficult, often agonizing, emotional, ethical, and spiritual issues. The needs of caregivers, and the strengths and vulnerabilities of their relationship with the persons they care for, also demand attention.⁶
3. There is a range in the abilities and the severity and rate of decline of persons living with progressive cognitive impairments, with variations even among those diagnosed with the same disorder. Each person's experiences and circumstances, as well as those of their caregivers, are unique and change over time. It is important, therefore, to base the care of persons living with

M.C. Angermeyer, "Mortality in Dementia," *Neuroepidemiology* 25.3 (2005): 153-62. Thus the term *progressive cognitive impairments* as used in this statement does not include every single type of *dementia* listed and defined in the *International Statistical Classification of Disorders and Related Health Problems, Tenth Edition (ICD-10)* (Geneva: World Health Organization, 2007) or the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision (DSM-IV-TR)* (Washington, D.C.: American Psychiatric Association, 2000).

² Daniel W. O'Connor, David Ames, Betina Gardner, and Madeleine King, "Psychosocial Treatments of Behavior Symptoms in Dementia: A Systematic Review of Reports Meeting Quality Standards," *International Psychogeriatrics* 21.2 (April 2009): 225-240; Daniel W. O'Connor, David Ames, Betina Gardner, and Madeleine King, "Psychosocial Treatments of Psychological Symptoms in Dementia: A Systematic Review of Reports Meeting Quality Standards," *International Psychogeriatrics* 21.2 (April 2009): 241-51.

³ The prevalence of all types of dementia in older persons doubles every five years from ages 65 to 85. The trend continues after that for women but not for men. See M.M. Corrada, R. Brookmeyer, D. Berlau et al., "Prevalence of Dementia after Age 90: Results from the 90+ Study," *Neurology* 71.5 (July 29, 2008): 337-43.

⁴ Stephen Waring, Rachele Doody, Valory Pavlik et al., "Survival Among Patients with Dementia from a Large Multi-Ethnic Population," *Alzheimer Disease and Associated Disorders* 19.4 (Oct./Dec., 2005): 178-83.

⁵ Cleusa P. Ferri, Martin Prince, Carol Brayne et al., "Global Prevalence of Dementia : A Delphi Consensus Study," *Lancet* 366.9503 (Dec. 17, 2005): 2112-17. See also: World Health Organization, *World Health Report 2002: Reducing Risks, Promoting Healthy Life* (Geneva: World Health Organization, 2002) and Alzheimer's Disease International, "Prevalence of Dementia Worldwide", available at: <http://www.alz.co.uk/adi/pdf/prevalence.pdf>.

⁶ Astri Ablitt, Gregory V. Jones, and Jane Muers, "Living with Dementia: A Systematic Review of the Influence of Relationship Factors," *Aging and Mental Health* 13.4 (July 2009): 497-511.

progressive cognitive impairments and their caregivers on accurate assessments and to ensure that their care is appropriate to their particular and current abilities, needs, and circumstances.⁷

4. Persons living with progressive cognitive impairments and their caregivers are among the most disadvantaged and vulnerable groups in our communities. They are invisible, their needs tend to be overlooked or given low priority, and the amount and quality of the supports that they receive are frequently inadequate or inappropriate. There is often a social stigma attached to being an elderly person and living with progressive cognitive impairments.⁸

The Scope of this Statement

5. The aims of this statement are, first, to give philosophical and theological grounds for valuing persons living with progressive cognitive impairments *as persons* and for committing to provide them with appropriate and loving care; second, to articulate some principles to guide ethical decision making regarding such care; third, to offer recommendations on a few crucial ethical issues.
6. This statement is addressed to Catholics and all members of society because providing appropriate and loving care to persons living with progressive cognitive impairments and their caregivers ought to concern us all.

Foundations

The participants in this colloquium affirm the following philosophical and theological positions.

Intrinsic Dignity and Worth of Human Beings

7. Human beings *as such* are persons with intrinsic dignity and worth.⁹ Since progressive cognitive impairments do not in any way undermine or reduce one's humanity, those living

⁷ Tom Kitwood, *Dementia Reconsidered: The Person Comes First* (Buckingham, U.K.: Open University Press, 1997); Julian C. Hughes, "Views of the Person with Dementia," *Journal of Medical Ethics* 27.2 (April 2001): 86-91.

⁸ In this colloquium, Julian C. Hughes drew attention to the notion that persons living with progressive cognitive impairments lose abilities not just because of brain pathology but also because of the negative responses of others to them. See Steve R. Sabat, *The Experience of Alzheimer's Disease: Life through a Tangled Veil* (Oxford: Blackwells 2001).

⁹ Daniel P. Sulmasy has distinguished three senses of *human dignity* in Western philosophy that often get muddled in discussions in ethics. *Intrinsic human dignity*, which is the sense of dignity emphasized in this statement, is the value that human beings have simply by virtue of the fact that they are human beings, i.e., their ontological value. Intrinsic dignity is not based on "any social standing, ability to evoke admiration, or any particular set of talents, skills, or powers." *Attributed human dignity* is the value that human beings confer upon others by choice and convention. *Inflorescent human dignity* is the value of human excellence or virtues. Inflorescent dignity presupposes the intrinsic dignity of all human beings but refers to the value of the habits and conditions that lead human beings to blossom, flourish or thrive as human beings. For an elaboration on these three senses of human dignity, see Sulmasy's "Dignity and Bioethics: History, Theory, and Selected Applications," in *Human Dignity and Bioethics: Essays Commissioned by the President's Council on Bioethics* (Washington, D.C.: The President's Council on Bioethics, 2008). Mette Lebech has written that the "fundamental value" of another human being is recognized best in our experiences of love and friendship. See

with such impairments are persons and continue to have moral status. They are to be valued and treated as having dignity and worth equal to that of other members of the human family.

Christians understand the intrinsic dignity and worth of human beings to rest, above all, on God's love for every human being and the call of every human being to communion with God.¹⁰

Unity of the Human Being

8. Every human being is a unity and a totality of biological, psychological (emotional and intellectual), social and spiritual aspects.¹¹ No human being is reducible to only a part, or function, of his or her whole being. For example, the irreversible loss or destruction of intellectual capacities in a person does not entail that he or she is reduced to being only a biological entity deprived of his or her spiritual capacities.

The notion of the unity of body and soul is fundamental to the Christian understanding of the human person and of God's plan of creation and redemption. It underlies the Catholic Church's teachings on the order of creation, the incarnation of Christ, his passion, death, and resurrection, the institution of the Church and the sacraments, and the resurrection of the dead.¹²

Identity of the Human Being

9. Undergoing change (whether developing or declining) is a reality in every human life from its beginning to its end. The loss of intellectual and other cognitive capacities in a human being does not entail the destruction of his or her identity as a human being and value as a person.¹³

Mette Lebeck, *On the Problem of Human Dignity. A Hermeneutical and Phenomenological Investigation* (Würzburg, Germany: Verlag Königshausen & Neumann, 2009).

¹⁰ Vatican Council II, *Gaudium et spes* (1965), n. 19.

¹¹ International Association of Catholic Bioethicists, "Statement on Regenerative Medicine and Stem Cell Research," *National Catholic Bioethics Quarterly* 8.2 (2008): 322-39, n. 3. See also Daniel P. Sulmasy, A Biopsychosocial-Spiritual Model for the Care of Patients at the End of Life," *The Gerontologist*, 42.Special Issue III (2002): 24-33.

¹² For an elaboration, see International Theological Commission, *Communion and Stewardship: Human Persons Created in the Image of God*, n. 27-31 and Benedict XVI, *Deus Caritas est*, n. 5.

¹³ The philosophical question of whether there is "still a person" in someone living with progressive cognitive impairments is much debated. See Julian C. Hughes, S. J. Louw, and Steven R. Sabat, eds., *Dementia: Mind, Meaning, and the Person* (Oxford: Oxford University Press, 2006). This question accounts for a great part of the anguish and uncertainty often experienced by loved ones and other care providers of persons living with progressive cognitive impairments. An influential view in society, advocated by thinkers such as Michael Tooley and Derek Parfit, holds that radical changes in a human being, such as those caused by progressive cognitive impairments, destroy or diminish personhood. The participants in this colloquium rejected this position. The personhood of people living with progressive cognitive impairments was affirmed in several complementary ways: Some participants presented arguments drawn from Aristotelian-Thomistic metaphysics or based on contemporary philosophical notions such as "natural kinds". Others appealed to notions such as "forms of life" and "embodiment" (based on the later work of Ludwig Wittgenstein), "incarnate meaning" (from Bernard Lonergan's work), and "empathy" (from Edith Stein's writings), and also to empirical research, to ground a broad conception of how one's personhood is manifest, besides rationality and self-direction (e.g., conveying meaning through one's bodily senses and movements, emotions, relationships). Still others

For Christians, God’s love and care for every human being is unconditional and endures through all changes and adversities in a human being’s life.¹⁴

Human Relationships

10. Human beings are inherently relational through knowing and loving others and being dependent on one another. Persons living with progressive cognitive impairments always have the capacity to receive care and love from others even if their capacity to reciprocate may be limited. Caregivers may discover and express through their loving service and support of persons living with progressive cognitive impairments what is intrinsic to their own humanity.

Christians affirm that human beings are inherently relational, being created in the image and likeness of God who is Love [*Caritas*] and a communion of three Persons—Father, Son, and Holy Spirit.¹⁵ Through faith and grace, human beings are enabled to share in this divine life.

11. Relationships persist even when intellectual and other cognitive abilities of human beings are lost. The communities to which persons living with progressive cognitive impairments belong can help to sustain memories and a continuity with their past in the midst of changes, and support the decision making of such persons to the extent that they are capable.¹⁶

Christian love in the sense of *caritas* entails a commitment to care steadfastly for the one who is loved. Ultimately, this love is a participation in the love of God who never abandons any human being.

12. The first relationships among human beings are those of the family. The reciprocal responsibility of children to take care of dependent parents is accepted in many cultures and philosophies. This is a reflection of the intrinsic human need to protect and foster the common good. On the level of society, the obligation of children to care for aging parents is one basis for promoting intergenerational justice.¹⁷

emphasized that love entails an unwavering commitment to another person, whether or not there are detectable signs of a familiar personality.

¹⁴ The following words in a speech by Pope John Paul II regarding persons in a “vegetative state” are also relevant to persons living with progressive cognitive impairments: “The loving gaze of God the Father continues to fall upon them, acknowledging them as his sons and daughters, especially in need of help.” See John Paul II, *Address to the Participants in the International Congress on “Life-Sustaining Treatments and Vegetative State: Scientific and Ethical Dilemmas,”* (March 20, 2004), n. 3.

¹⁵ Vatican Council II, *Gaudium et spes* (1965), n. 12: “For by his innermost nature man is a social being, and unless he relates himself to others he can neither live nor develop his potential.” See also International Theological Commission, *Communion and Stewardship: Human Persons Created in the Image of God*, n. 42-43, and John Paul II, *Redemptor hominis* (1979), n.10.

¹⁶ An important role for loved ones of a person living with progressive cognitive impairments is to provide guidance for decision making regarding that person’s values, beliefs, and life plans. See Linda Scheirton, “Ethical Dimensions of Alzheimer’s Disease Decision Making: The Need for Early Patient Intervention. In Ruth B. Purtilo and Henk AM.J. ten Have, eds., *Ethical Foundations of Palliative Care for Alzheimer’s Disease* (Baltimore: Johns Hopkins University Press, 2004), 261-77.

¹⁷ This obligation may have legitimate limits. For example, it may sometimes be difficult or impossible for children to give care because of a lack of resources, geographic separation, or other family responsibilities.

For Christians, the fourth of God’s Ten Commandments, “Honor your father and mother,”¹⁸ reveals that the responsibility of children to respect and care for parents when they are dependent is not only demanded by justice but also a manifestation of gratitude and self-giving love.¹⁹ The honor and love that are the basis of this commandment can be understood to extend to all members of a family, and ultimately, this way of being together in a family is the social foundation of the state.²⁰ The principle of subsidiarity in the social teaching of the Catholic Church can be applied to affirm the important role of family caregivers and society’s obligation to provide as much help (*subsidium*) as possible to them.²¹

Stewardship of Human Life

13. Human beings are naturally inclined to preserve their lives, to contribute to the common good, and to protect the innocent.²² Individuals have a duty to take care of their respective lives and health and to prevent diseases such as those that cause progressive cognitive impairments as much as possible. They have a reasonable expectation of assistance from the community for their health care needs, including preventive care, and the corresponding duties to respect the life of others and to contribute to looking after their health needs.

For Christians, life is God’s gift, and human beings have a responsibility to be good stewards of this gift, including taking available and appropriate measures to maintain their own health and life, reverencing the lives of others, and contributing to the community’s provision of health care.

Human Limitations

14. Human beings are finite and mortal beings who live in a material world. Illness, aging, and dying are realities in every human life. Health care resources and the capacities of caregivers have limits as well.

For Christians, the responsibility to preserve one’s own life is not an absolute and does not override all other responsibilities. While stewardship of life entails that human beings should take available and appropriate measures to maintain health and preserve life, the Christian acknowledges that these measures have limits, and that the ultimate human response to the inevitability of infirmity, aging, and dying ought to be acceptance, surrender to, and trust in God. The ultimate purpose of human existence is union with God and not longevity. Pope

Aristotle, however, thought that children could never adequately repay their parents for what they owe them; see *Nicomachean Ethics* 1164b5.

¹⁸ Exodus 20:12; Deuteronomy 5:16; cf. Ephesians 6:1-3.

¹⁹ John Paul II, *Letter to Families* (1994), n.15.

²⁰ John Paul II, *Familiaris consortio* (1981), n. 42.

²¹ An early articulation of the principle of subsidiarity is contained in Pius XI, *Quadragesimo anno* (1931): “...it is a grave injustice and at the same time a grave evil and disturbance of right order to assign to a greater and higher association what lesser and subordinate organizations can do. For every social activity ought of its nature to furnish help to the members of the body social, and never destroy and absorb them.” *The Compendium of the Social Doctrine of the Church* (Vatican City: Libreria Editrice Vaticana, 2004) explains that the principle can be understood in a positive sense as requiring all societies at a higher level of organization to support, promote, and develop the capacities of those at a lower level. See *op. cit.*, n. 186.

²² Thomas Aquinas, Aquinas, *Summa theologiae* II-II, q.64.5; *De regno, ad regem Cypri* I.1, no. 8.

Benedict XVI has written: “To eliminate death or to postpone it more or less indefinitely...for the individual would bring no benefit.”²³

15. Suffering is a reality of human existence. Reason alone can offer no complete explanation or solution for the mystery of suffering. Nevertheless, many human beings can experience hope even in the midst of difficult challenges, the anguish of suffering, or attending to one who is suffering.

For Christians, human suffering calls for communion and solidarity, and ought to be addressed by appropriate and loving care whenever possible.²⁴ Ultimately, human suffering has its deepest meaning and saving value in the passion, death, and resurrection of Christ.²⁵

Solidarity, Social Justice, and Self-giving Love (*Caritas*)

16. Human interdependency entails solidarity among all members of society and a concern to promote conditions for the participation of all in society. An individual who is vulnerable or dependent due to illness or disability is still a member of society.

For Christians, honoring and caring for those who are treated as the least members of society is a commandment of Christ.²⁶ The preferential option for the poor, the marginalized, and the vulnerable, i.e., showing special concern for them, is an important component of the social teaching of the Catholic Church.²⁷ Social justice entails that societies prefer systems of distributing health care resources that most help the needy and the vulnerable, including persons living with progressive cognitive impairments and their caregivers.

At the heart of the Church’s teachings on social justice is self-giving love (*caritas*), whose source is God’s love.²⁸ Christians seek to follow the example of Jesus Christ, the Son of God, who loved all human beings and gave himself for them.²⁹ Self-giving love goes beyond and completes social justice by urging individuals who care for the needy and vulnerable to do so with heartfelt concern.³⁰ “Seeing with the eyes of Christ, I can give to others much more than their outward necessities; I can give them the look of love which they crave.”³¹

²³ Benedict XVI, *Spe salvi* (2007), n. 11. Awareness of the finitude of human life, however, can never justify forgoing ordinary (i.e., morally obligatory) care and treatment with the intention thereby of ending one’s own life or that of another person.

²⁴ John Paul II, *Salvifici doloris* (1984), n. 8; Benedict XVI, *Deus Caritas est* (2005), n. 31 (a).

²⁵ John Paul II, *Salvifici doloris* (1984), n. 19, 21, 23.

²⁶ Matthew 25:31-46 and 1 Cor. 12:20-26.

²⁷ The term *preferential option for the poor* was first coined by Gustavo Gutiérrez in 1967, although the notion underlying it has biblical and patristic roots. The term was adopted in the documents of the Latin American Bishops’ Conference meeting in Medellín and Puebla, and also subsequently in papal documents, e.g. John Paul II, *Tertio millennio adveniente* (1994), n. 51: “...if we recall that Jesus came to ‘preach the good news to the poor’ (Matthew 11:5; Luke 7:22), how can we fail to lay greater emphasis on the Church’s preferential option for the poor and the outcast?” See also: Thomas Massaro, “A Preferential Option for the Poor: Historical and Theological Foundations.” In: Jos V.M. Welie and J.L. Kissell, eds., *Jesuit Health Sciences and the Promotion of Justice: An Invitation to a Discussion* (Milwaukee, WI: Marquette University Press, 2004), 69-92.

²⁸ Benedict XVI, *Veritas in caritate* (2009): n. 2.

²⁹ Galatians 2:20. See also Benedict XVI, *Deus Caritas est* (2005): n. 18.

³⁰ Benedict XVI, *Deus Caritas est* (2005): n. 31 (a).

³¹ Benedict XVI, *Deus Caritas est* (2005) : n. 18.

Ethical Principles³²

17. Some of the most difficult and perplexing challenges faced by persons living with progressive cognitive impairments and their caregivers are ethical issues. Based on the foundations articulated above, the participants of this colloquium offer the following ethical principles as guides to decision making. These principles are attempts to articulate what “doing good, and avoiding harm” and promoting a culture of ethical care entail practically in supporting persons living with progressive cognitive impairments and their caregivers. This list of principles is not meant to be taken as complete. The elaborations of each principle do not convey all that could be said about that principle. The first principle is the basis for all the other principles. The ordering of the remaining principles does not necessarily indicate a priority of importance. Conflicts may sometimes arise in applying these principles. Seeking the advice of appropriate members of a person’s community (e.g., family, other caregivers, clergy), ethics consultation, and counseling may help to address some of these conflicts. Ethical decisions regarding the care of persons living with progressive cognitive impairments require the prudent application of general principles, such as the ones outlined below, to the particular contexts of individuals and their caregivers.
- a. **Respect intrinsic dignity:** Treat persons living with progressive cognitive impairments as persons and avoid harming them. Do not only mourn their losses but acknowledge, encourage, and support their present abilities, while honoring their past and fostering their future possibilities.
 - b. **Encourage participation:** Enable persons living with progressive cognitive impairments to be involved in their communities without stigma.
 - c. **Ensure that care is holistic:** Provide care to persons living with progressive cognitive impairments that fosters as much as possible their integrity as human beings with a biological, psychological (emotional and intellectual), social, and spiritual nature.
 - d. **Be person-centered in providing care:** Provide care to persons living with progressive cognitive impairments that best addresses their present and particular needs, taking into account their past wishes and beliefs.
 - e. **Support families and other caregivers:** Respect the bond that exists among family members and the role of family caregivers. Whenever appropriate, consider the needs of persons living with progressive cognitive impairments jointly with those of their family caregivers. Strengthen family relationships. Motivate and help all caregivers to provide appropriate and compassionate care to the extent that they are able, and to cope with the challenges of care giving.

³² These principles were developed initially by examining those contained in Jos V.M. Welie and Bert Gordijn, “The Declaration of Berg en Dal on the Ethical Principles Guiding Palliative Care of Persons with Alzheimer’s Disease-Commentary,” In: Ruth B. Purtilo and Henk A.M.J. ten Have, eds., *Ethical Foundations of Palliative Care for Alzheimer Disease* (Baltimore and London: Johns Hopkins University Press, 2004): Appendix A, 343-47. During this colloquium, Jos Welie helped to propose adaptations and revisions of the principles in the Berg en Dal Declaration for discussion.

- f. **Judge appropriate limits of treatment:** When planning medical treatments for persons living with progressive cognitive impairments, be mindful that such interventions cannot, at present, cure those impairments but may only slow their progression and relieve some of the symptoms. The obligation to preserve life is not an absolute, however, we are always morally bound to provide reasonable care and treatment in the person’s circumstances.
- g. **Respect the appropriate level of responsibility for care and provide supports:** Care for persons living with progressive cognitive impairments should be given at the organizational level that is best able to assume responsibility for that care and provide appropriate resources.
- h. **Allocate according to the demands of social justice.** Distribute health care resources with special concern for persons living with progressive cognitive impairments and their caregivers, while being mindful of other important social goods.

Recommendations

Based on the foundations and ethical principles outlined above, participants in this colloquium offer these recommendations, with some examples.

- 18. All should do their utmost to cultivate respect for the intrinsic dignity and worth of persons living with progressive cognitive impairments.
 - a. We should avoid language, attitudes and behaviors that depersonalize, devalue, and lead to the stigmatization of persons living with progressive cognitive impairments (e.g., fear, disgust, contempt, inappropriate ‘taking over’ of their abilities, ignoring them).
 - b. We should encourage opportunities in our communities to interact with and befriend persons living with progressive cognitive impairments (e.g., through shared activities between younger and older persons, visits to homes and care facilities).
 - c. We should take steps to protect persons living with progressive cognitive impairments from neglect or abuse, including identifying and addressing risk factors for such harm.
 - d. We should challenge those cultures and ways of thinking that hold that aging, disability, dependency on others, suffering, and death lack meaning. We should present reasons, such as the ones in this statement, for society’s commitment to care for persons living with progressive cognitive impairments and for hope.³³ Persons living with progressive cognitive impairments should never be made to regard themselves, or be regarded, merely as being a burden to their caregivers or to society, or as having a “duty to die.”
 - e. We should educate patients and families on the distinction between intentional killing that is always morally wrong (e.g., assisted suicide or euthanasia) and deciding to forgo medical interventions that are “extraordinary” (i.e., morally optional) because such

³³ Stephen Post has written on the tendencies of some societies and cultures to be “hyper-cognitivist”. That is, they privilege rationality and independence in decision making as the criteria for moral worth. See Stephen G. Post, *The Moral Challenge of Alzheimer Disease: Ethical Issues from Diagnosis to Dying*, 2d ed., rev. (Baltimore and London: Johns Hopkins University Press, 2000).

interventions present little hope of likely benefit or are excessively burdensome to a dying person.³⁴

- f. We should support a different response to human limitation and suffering than assisted suicide and euthanasia (e.g., by promoting effective and ethical palliative care, and enhancing relational, psychological, and spiritual resources at the end of life). We should seek legal protection for vulnerable persons as well as for health professionals and institutions that oppose assisted suicide and euthanasia.
19. Within our families and organizations, we should enable those living with progressive cognitive impairments and their caregivers to receive as much care as possible that is holistic, person- and family-centered. We should also promote such care throughout the community.
- a. We should involve persons living with progressive cognitive impairments in decisions regarding their care to the extent that they are capable, recognizing that they may require supports because of specific vulnerabilities. Attention to a person's past expressed wishes, affective and behavioral cues, the involvement of family members and others who know the person well, and assistance from ethics and pastoral care consultants may often contribute to discerning the person's values and what he or she

³⁴ Euthanasia is "an act or omission which of itself and by intention causes death, with the purpose of eliminating all suffering." See John Paul II, *Evangelium vitae* (1995), n. 65. The Congregation for the Doctrine of the Faith's document, *Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration* (2007), clarified that artificial nutrition and hydration are in principle ordinary, while not excluding the possibility that such an intervention might become extraordinary if it were "excessively burdensome for the patient" or when it might "cause significant physical discomfort." The bishops of the U.S.A. approved an ethical directive that states: "In principle, there is an obligation to provide patients with food and water, including medically assisted nutrition and hydration for those who cannot take food orally. This obligation extends to patients in chronic and presumably irreversible conditions (e.g., the 'persistent vegetative state') who can reasonably be expected to live indefinitely if given such care. Medically assisted nutrition and hydration become morally optional when they cannot reasonably be expected to prolong life or when they would be 'excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means employed.' For instance, as a patient draws close to inevitable death from an underlying progressive and fatal condition, certain measures to provide nutrition and hydration may become excessively burdensome and therefore not obligatory in light of their very limited ability to prolong life or provide comfort." (revision to United States Conference of Catholic Bishops, *Ethical and Religious Directives for Catholic Health Care Services*, Fourth Edition, 2001, no. 58, approved in November, 2009). In this colloquium, Peter Gummere presented on the issue of providing artificial nutrition and hydration to persons living with progressive cognitive impairments. For an elaboration, see his "Assisted Nutrition and Hydration in Advanced Dementia of the Alzheimer's Type: An Ethical Analysis," *National Catholic Bioethics Quarterly* 8.2 (Summer 2008): 291-305. For a different view, see John S. Howland, "A Defense of Assisted Nutrition and Hydration in Patients with Dementia," *National Catholic Bioethics Quarterly* 9.4 (Winter 2009): 697-710. The participants in this colloquium affirmed the value of assistance in feeding of persons living with progressive cognitive impairments that are as person- and family-centred as possible (e.g., handfeeding in appropriate circumstances). They agreed that the presence of progressive cognitive impairments in a person can never be the *sole* justification for caregivers withholding or withdrawing appropriate ordinary care from them; other factors should be considered on a personal basis, such as the extent to which the person is able to assimilate food and fluid, burdens, and proximity to death.

would desire in the present circumstances, and to determining ethical ways of addressing the person's needs.³⁵

- b. If the safety of a person living with progressive cognitive impairments or that of caregivers is a concern, the least intrusive and restrictive options appropriate for the person's needs should always be tried before more intrusive or restrictive ones (e.g., changing possible sources of stress or distress in the person's environment before introducing medication or restraints for challenging behaviours).
- c. We should foster practices that are person- and family-centered as much as possible (e.g., handfeeding in appropriate circumstances³⁶, enabling persons to live in their communities, fostering stimulating environments and activities). We should respond to the tensions and the ethical conflicts that may sometimes arise within families, as best we can, through such means as reflection, consultation, discussion, counseling, spiritual care, and other appropriate interventions and supports.
- d. We should encourage advance health care and end-of-life planning by persons diagnosed with progressive cognitive impairments, when they are capable, with their caregivers. Because written advance directives or living wills have their limitations, we should encourage persons to designate someone to represent them when they are not capable of making decisions regarding their care. If written advance directives are used, they should be formulated carefully and supplemented with discussions with the designated proxy or surrogate decision maker and family members.³⁷

³⁵ There were many ethical issues surrounding decision making regarding the care of persons living with progressive cognitive impairments that were raised during this colloquium, but there was insufficient time to discuss them in depth. The most contentious among these issues include the relative moral weight of expressions of last-known preferences in advance directives or "living wills", substituted or surrogate judgments, and best-interest judgments that involve input from health care providers—for more on this issue, see Jos V.M. Welie, "The Tendency of Contemporary Decision-making Strategies to Deny the Condition of Alzheimer Disease," In: Ruth B. Purtilo and Henk A.M.J. ten Have, eds., *Ethical Foundations of Palliative Care for Alzheimer Disease* (Baltimore and London: Johns Hopkins University Press, 2004): 163-80; whether following the advance directive of a person presently assessed to be incapable of decision making should be held to a different ethical standard than that of a capable person's refusal of treatment—Linda Scheirton initiated discussion of this issue in a communication presented at this colloquium; what to make of new models in ethics and law such as supported decision making in regard to persons living with progressive cognitive impairments—Jane Adolphe addressed this issue in her paper for this colloquium. Given the range of opinions emerging from the limited discussion of these issues at the colloquium, participants agreed that the topic of decision making for persons assessed to lack decision making capacities requires further careful investigation and reflection by Catholic ethicists, and some participants suggested this topic for a future IACB International Colloquium.

³⁶ Carol Taylor initiated discussion of this issue in her paper for this colloquium. There was widespread agreement among participants that feeding and hydrating by mouth, with supplements if necessary, should be offered whenever possible to persons living with progressive cognitive impairments who cannot feed themselves but are able to swallow and tolerate what is given.

³⁷ Catholic Health Australia has developed a model statement for future health care that is available online at: <http://www.cha.org.au>. The National Catholic Bioethics Center in the U.S. has published *A Catholic Guide to End-of-Life Decisions* (1997) that includes an example of a health-care proxy/ advance medical directive.

- e. We should promote excellent training of health professionals who care for persons living with progressive cognitive impairments and their caregivers.³⁸ Health professionals should have the opportunity and support to learn how to provide holistic, person- and family-centered care. They should be educated on the particular health issues relating to progressive cognitive impairments (e.g., accurate diagnosis and effective or promising approaches to treatment and care).³⁹ They should also receive training and support regarding ethics, spirituality, and dying that is appropriate for their work.
- f. We should ensure that spiritual care is offered as an important and integral component of providing care to persons living with progressive cognitive impairments and their caregivers.⁴⁰
- g. Health care organizations, especially Catholic ones, that serve persons living with progressive cognitive impairments and their caregivers should commit to providing exemplary and ethical care to them and develop an organizational culture that is accountable to that commitment (e.g., whenever possible, through educating and formation of their staff, regular audits, research to improve care, and providing ample resources for ethics and pastoral care).
- h. Catholic parishes, in particular, are encouraged to develop as much as possible structures to provide pastoral care for persons living with progressive cognitive impairments and their caregivers that addresses their material, psychological, social, and spiritual needs (e.g., praying for their needs, facilitating their reception of the sacraments, counseling, sponsoring support groups and education, organizing volunteers for home visits, assistance with the activities of living, social events, or respite).⁴¹

³⁸ An example presented by Wilhemina Hoffman in this colloquium is the specialist training on dementia care using a palliative care approach that is offered to nurses and other health professionals in Sweden in cooperation with the Silviahemmet Foundation. For more information, see: <http://www.sylviahemmet.se>.

³⁹ In a paper for this colloquium, Myles N. Sheehan noted: “[T]here is an urgency in providing physicians and other health care providers who can accurately diagnose cognitive changes, differentiate between emergent conditions, and limit the number of older persons with treatable illness who may be inaccurately diagnosed with a dementia, with potentially severe consequences including institutionalization and prolonged mental anguish.” There was some discussion, during the colloquium, of the ethical problems surrounding failure to diagnose progressive cognitive impairments, delayed diagnosis, and misdiagnosis, all of which may lead to providing inappropriate interventions or not initiating appropriate ones. There were discussions also regarding disclosure of a diagnosis and the challenge presented by the notion of “mild cognitive impairment” (MCI), which is taken to be an early stage of a progressive cognitive impairment, but which in some people might only reflect the normal process of aging. There are, therefore, worries about people being made anxious by an inappropriate medicalizing label. There is even now the concept of “minimal cognitive impairment” that is even more difficult to differentiate from normal aging.

⁴⁰ An example is the Dementia and Spirituality Project of the Caritas Social Action Network (CSAN), which was initiated by the Catholic Bishops’ Conference of England and Wales. See <http://www.caritas-socialaction.uk/>.

⁴¹ Pastoral care here is defined in terms of the church’s three-fold responsibility of proclaiming the word of God (*kerygma-martyria*), celebrating the sacraments (*leitourgia*) and exercising the ministry of charity (*diakonia*). For an informative study with concrete recommendations for parishes, see Helene L. McCormack, *And We Shall*

20. We should make every effort to advocate that governments and other allocators of resources, especially Catholic health care and educational institutions, include among their priorities the provision of adequate and appropriate care to persons living with progressive cognitive impairments and their caregivers, as well as education and ethical research for improving such care.
- a. We should examine the values on which criteria for distributing health resources in our communities and organizations are based, and oppose criteria that focus exclusively on efficiency, maximizing profit, and utilitarian ethics (e.g., by those that rely solely on Quality-Adjusted Life Years or “QALY” calculations).⁴² Such approaches fail to take into consideration the integral good of persons as elaborated in this statement.
 - b. We should support ethical research to improve the treatment and care of persons living with progressive cognitive impairments (e.g., medication, holistic and person-centered interventions, ethical research using adult stem cells that has a reasonable hope of developing therapies). Because of the vulnerabilities of persons living with progressive cognitive impairments, the ethical management of research involving their participation requires careful attention to the likelihood of benefit and of risks of significant harm, issues surrounding consent, privacy and confidentiality, and access to the benefits of the investigations. We should not unduly impede or restrict research that is likely to be beneficial to persons living with progressive cognitive impairments, individually or as a group (e.g., qualitative research looking at person-centered care). We should, however, resist the raising of false expectations and hopes regarding the potential of some programs of research to generate cures or therapies for persons living with progressive cognitive impairments when there is little reliable theoretical or empirical basis for such claims.
 - c. Because most persons with progressive cognitive impairments in the world live in less affluent societies, representatives of these societies should be involved in discussions on the global level regarding allocating resources for the care of persons living with progressive cognitive impairments and their caregivers, and for prevention of progressive cognitive impairments.

Conclusion

21. Recalling the theme of the Fourth International Colloquium of the International Association of Catholic Bioethicists (IACB), “Human Life with Progressive Cognitive Impairments: Caring and Giving Hope in a World of Change,” the main conclusions of this colloquium may be summarized by stating that, for persons experiencing progressive cognitive impairments and their loved ones, life has changed but not ended. Hope, even in the bleakest circumstances, can be engendered and sustained by a community that provides appropriate and loving care.

Honour Our Fathers and Our Mothers: The Role of Church in Outreach Ministry to the Elderly and Shut-Ins (Montreal: Concordia University and the Lonergan Centre for Ethical Reflection, 2004).

⁴² Anthony Fisher, “The Ethics of Health Care Allocation,” *Catholic Medical Quarterly* 44.4 (May 1993): 13-20. See also Anthony Fisher and Luke Gormally, eds., *Healthcare Allocation: An Ethical Framework for Public Policy* (London: Linacre Centre, 2001).

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