# FINAL DRAFT

Ministry to the Dying Working Group

Report to Bishop-in-Council (following Synod Resolution 222/17)

FEBRUARY 2019

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## 1. Background:

#### **Charter:**

The Ministry to the Dying Working Group was established as a result of Synod Resolution 222/17.

"Resolved that this synod requests Bishop-in-Council to convene a working group to investigate the theological and pastoral implications of ministry to the dying, including assisted dying,"

# Membership:

Bishop-in-Council resolved the following be invited to join the group: Archdeacon Muston (convenor), the Rev. Graham Toohill, the Rev. Fran Grimes, Mrs Denise Vranek, the Rev. Nikolai Blaskow, Ms Therese Tierney (consultant), the Rev. Dean Spaulding, Ms Sue Fordham (minute taker and compiler of the report), The Rev. Sue Jacka.

Others later co-opted to the working group were Mrs Kaye Thurbon who became chairperson, the Rev. David Head and Cynthia Grove. Membership fluctuated over time.

**Terms of Reference:** (determined by the working group at its initial meeting)

- The theological underpinnings of ministry to the dying including those who opt for physician assisted dying.
- Medical and health implications.
- Pastoral implications.
- Educational resources for those involved in pastoral care of the dying.

#### Approach to developing our report

At our third meeting, in January 2018, the Group decided we had an opportunity not only to respond to Synod's request but also to make a contribution to the broader community discussion on voluntary assisted dying. So, our approach to developing our report became one of developmental discussion. Members in the group with a variety of theological positions and expertise presented papers for consideration. As a result of these discussions, given the uniqueness of each human being and the complexity of each end of life situation, we adopted the Transcendent Moral Ethics Model as the most appropriate way to fulfil our task, recognising the uniqueness of each individual case.

# 2. The Legislation: Key Points:

The Voluntary Assisted Dying Act 2017 is succinctly summarised in Endpaper 1 (Voluntary Assisted dying Act 2017 Authorised Version as at 1 July 2018 at 1 July 2018 Summary).

#### The outline includes:

- Purposes of the Act
- Commencement time: 19 June 2019
- Definitions
- Decision making capacity requirements of person seeking assisted dying.
- Principles underpinning the Act.
- When a person may access voluntary assisted dying.
- Conscientious objection of registered health practitioners who have the right to refuse to provide information and/or participate in the process.
- Eligibility criteria for access to voluntary assisted dying
- Process for accessing the service (no. 10 no. 66)\*
- Notification of cause of death
- Review by VCAT
- Notifications and protections from liability
- Offences under the Act
- Voluntary Assisted Dying Review Board\*
- General
- Consequential Amendments.

The working group agreed that the Act was extremely rigorous. In framing the legislation the Victorian Government had taken into account the weaknesses in the requirements and the implementation of overseas legislation and of the ongoing experiences of overseas countries. Given the protections built into the act and the requirements of all parties in terms of compliance and the severe penalties for breaches of compliance, and while no process or legislation can ever be entirely risk free, we hope that abuse of this legislation, while theoretically possible to occur, is unlikely.

It is important to stress that in our Report we are not advocating assisted dying or euthanasia, but rather how to minister, in love and compassion, not only to the person considering such a choice, but also to their family and friends.

\*At the beginning of January2019 the Victorian Government announced: The Alfred Hospital will be responsible for importing, preparing and supplying all the lethal medication to be used by Victoria's first voluntary assisted dying patients.

A team of pharmacists will be appointed to travel around the State to dispense the medication to ensure patients are provided with consistent information and unused medications are returned and destroyed. The specialised pharmacy service will report to the Voluntary Assisted Dying Review Board.

Former Supreme Court Judge, Betty King has been appointed Head of the Board.

# 3. Theological Framework:

After much discussion it was agreed that the following expressed the mind of the working group:

- We are all part of a common humanity created by God, in the complexity of gender, body shape and size, disability, race, culture and faith perspective.
- This complexity of humanity is always viewed for a Christian out of our Christian understanding of Jesus Christ as declared in the Gospels.
- All life is sacred to God and given to us by God.
- So, for a person of faith, life has a purpose and that purpose is to seek to fulfil the will and desire of God for us.
- The difficult and fraught question is when does life cease to be that wholeness of life God gives to us and desires for us in all its quality and meaning and ability to fully live? There is of course no agreement to the answer to this profound question.
- In the Christian faith, death is not the end of everything but a change into a new resurrection life in the spiritual realm of the kingdom of Heaven.
- Through the necessary prism of Jesus's life and teaching, we bring to our understanding of every human issue the great commandment of Jesus to love above all and in spite of all. This call to love above all is underlined by St Paul who declared that the greatest gift of all that is given by the Holy Spirit, is the gift of love.
- Therefore, in love, we view all life issues through the accompanying lenses of compassion, forgiveness, mercy and redemption.
- Faith enables us to deal with compassion and understanding the life and death issues surrounding the request for assisted dying such as the sense of fear and loss of hope, a loss of quality of life and of being no longer actually living but in reality, dying in a body kept alive by drugs and medical intervention. We believe there is a need for all people to have Advanced Medical Directives and access to good Palliative care

- and all patients need to know that they are able to withdraw active medical treatment if or when they so desire.
- Each person we meet who is facing the process of dying and imminent death, will do so uniquely and with varying degrees of peace, strength equanimity, uncertainty and fear. This is true for the one dying as well as for the family members and caring friends.
- How we offer pastoral care, emotional sensitivity and spiritual nurture will be necessarily informed and adjusted as we sit beside each unique other and openly hear and understand their needs and concerns without imposing our own agendas.
- A minority view in the Group was that the following should be added:
  We are not the determiners or possessors of our own life. It is not for us
  to determine or enable our own death in any way. Dying should be
  allowed to proceed at its own pace and thus affirm the trustworthiness
  of God's care for us. (The Blackwell Companion to Christian Ethics,
  pp.379-380 and Carole Bailey Stoneking: Euthanasia, Suicide, Letting
  Die, Chapter 28, Receiving Communion).

#### 4. Ethical Framework:

Because the working group represented a wide diversity of views on the issue of assisted dying, it became clear that dualistic argument would not achieve progress in allowing us to move beyond entrenched positions.

Dualism assumes that we live in an empirical world and that moral judgement can be made and justified rationally. Furthermore, dualism overlooks complexity in favour of dogmatic black and white, right and wrong polarities. Dualism sets rules and applies them rigidly, irrespective of the person or the circumstance.

Instead, the working group agreed to adopt a Transcendent Moral approach in seeking to determine an ethic in relation to physician assisted dying. (See Dr Sarah Bachelard: **Resurrection and Moral Imagination**, **Ashgate**, **2014**).

Transcendent Moral Ethics assumes that the person, in all his or her uniqueness, ought to be the centre of the determination, opposed to dualism's focus on application of an immutable rule to all. So, our approach should always be person centred rather than rule centred.

Transcendent Moral Ethics (TME) assumes that each person is unique, each circumstance unique, each moral dilemma unique. Given this, it takes more than a rational or dogmatic approach to resolve issues as they arise. In putting the person at the centre, we are able to see through the eyes of compassion, to see the interconnectedness of things and engage with the person in their uniqueness.

In his papers on Transcendent Moral Ethics, (**Some Thoughts on Ministering to the Dying**), the Rev Nikolai Blaskow details two cases to illustrate this approach, that of Sister Helen Prejean in dealing with a murderer and rapist and Raymond Gaita's experience in a psychiatric hospital. He concludes that using the Transcendent Moral approach allowed the carer, through unconditional love, to see the humanity in people in whom it had become obscured either by evil acts or madness.

In looking at the ethical issues involved in physician assisted dying through this lens the working group was able to acknowledge the individuality and complexity that must inevitably exist in every death as in every life.

#### 5. A Model for Pastoral Care:

This model has been developed in the context of the Theological and Ethical Frameworks set out above. Put simply: God is love and we are called to love God and our neighbour as ourselves.

The Anglican Church already has widely accepted pastoral care practices developed on a 'continuous improvement' basis and fixed as an integral part of theological training. The Resources list, incorporated in this report, gives additional material that covers the new voluntary assisted dying reality and in the Conclusions and Recommendations section there are suggestions as to what the Church might do in the event of inadequate palliative care provision.

The working group adopted the following as a guide to what could constitute good, universally available palliative care, consistent with our Christian world view. The absence of this may influence the advice, or counsel, given to a terminally ill person or their family and friends.

Palliative care is a vital service, always applicable, where there is no expectation that a person's illness can be cured.

The principles of good palliative care are:

• To provide relief from pain and other symptoms of terminal illness.

- To affirm life and regard dying as a normal process.
- To neither hasten nor postpone death.
- To integrate both psychological and spiritual aspects of patient care
- To offer a support system that enables the person to live as actively as possible until death.
- To help the family and friends cope during the person's illness and to manage their own bereavement.
- To involve a team to address the needs of the person and their family.
- To enhance the quality of life and positively influence the course of the illness.
- To work in conjunction with other therapies and investigations that may be needed to manage any clinical complications of the illness.

Palliative care is a holistic approach to caring for the dying person which acknowledges the God-given value and dignity of the individual's life, no matter the circumstances. It gives total care which is continuous, competent and concerned for the person and their family.

It fits perfectly with the Christian faith because it recognises and values the spiritual care of the person. This means that prayer, anointing with oil, Holy Communion, worship music, Bible reading and the Anglican Book of Common Prayer, (A Prayer Book for Australia), are all readily included, where appropriate, in palliative care.

When practised in a loving and supportive way, palliative care gives great comfort and, as far as it is possible, may enable the terminally ill person to die in peace, free of fear. (Sourced from WHO Definition of Palliative Care 2004.)

## 6. Conclusions and Recommendations:

Voluntary Physician Assisted Dying is a reality in Victoria. The Act was passed in 2017 and takes effect on 19 June 2019. Whether individuals in the church support the idea or not, it is a reality that we must deal with, clergy in parish or chaplaincy work, laity in pastoral care groups, all will be touched by the need to care for someone who makes the choice to bring an end to their suffering using the law as it now stands.

In dealing with this new reality as well as in caring for those who choose to die conventionally, there are some important things that we can do to help the dying and their families. Therefore, the working group recommends:

 That all people, irrespective of age or state of health, should be encouraged to make sure that they have a valid will, an Advanced Care Directive and make decisions about organ donation. These should be updated periodically as circumstances change and relatives

- should be made aware of the person's wishes. It is important that a copy of the will be kept with a lawyer or trustee, not with just a family member, to protect the intentions of the person.
- The Working Group strongly recommends that pastoral care training be given priority in our diocese and that it be offered in each of the three regions. While it is important to provide ongoing training for clergy and people in hospital and school chaplaincy, it is essential also to equip lay people at parish level involved in pastoral care. Some parishes already participate in Interdenominational pastoral care teams these could serve as a model for the diocese as a whole. This may also be a suitable basis for providing training in pastoral care.
  - i. That training and support could be made available to others in the community, including doctors, who feel inadequately equipped for the task of pastoral care.
  - ii. The use of the resources of Clinical Pastoral Education Trainers and Mentors in the Melbourne Diocese could be considered.
  - iii. Government agencies could be an inexpensive source of materials and training. The Department of Health and Human Services has been developing resources to support clinical and community professionals in their care for the emotional and pastoral needs of people accessing voluntary assisted dying as well as their families. The contact person for these resources is Jackie.kearney@dhs.vic.gov.au
  - That people or institutions who have any issues with voluntary physician assisted dying are encouraged to contact the Review Board set up under the Act, which both serves as a monitoring agency and an ongoing review agency. The church should note and use this board when required.
  - The Act is predicated on the existence of good, widely available palliative care. The church should become an advocate for such care and where is does not exist, lobby government for its provision.
  - Pastoral workers who feel unequal or disinclined to deal with people wanting access to voluntary physician assisted dying should not attempt to do so but direct the person elsewhere for support.
  - It must be noted that the Act requires medical practitioners who accept responsibility for voluntary assisted dying to inform the person of pastoral care and other options and at each stage in the process to inform them that they may discontinue the request and assessment process.

#### **Resources:**

- 1. Organisations:
  - Victorian Government Advanced Care Directives form
  - Victorian Government. Voluntary Assisted Dying Task Force. Guidance material to support the emotional and pastoral needs of the person and their family. <a href="mailto:Jackie.Kearney@dhhs.vic.gov.au">Jackie.Kearney@dhhs.vic.gov.au</a>
  - Palliative Care Victoria

Ph:1300 998 100

https://www.palliativecarevic.asn.au

www.agedcareguide.com.au

www.activebeat.com/health/PalliativeCare

Palliative Care Hospice

2/182 Victoria Pde

East Melbourne, Victoria 3002

Palliative Care Program – Health Vic

https://www2.health.vic.gov.au>palliativecare

- Baptcare Social Policy Paper: Assisted Dying.
- Australian Centre for Grief and Bereavement
   https://www.grief.org.au
   Webinars, training programs, on-line store, grief information sheets (downloadable) relating to, grief, how to help the grieving, grief and children, bereavement in the workplace.
- Dying With Dignity Victoria www.dwdv.org.au
- National Council for Palliative Care Resources. Coping with Bereavement/ Dying Matters. Handling bereavement, dying matters with an emphasis on suicide bereavement <a href="https://www.dyingmatters.org">https://www.dyingmatters.org</a>
- American Institute of Allied Health Professionals: Pastoral Care of The Families of the Dying, www.aihcp.org7infohanpt490
- Cancer Research U.K.
   Resources and Support when someone is dying/ Cancer in General,
   www.cancerresearchuk.org/about-cancer/coping/dyingwith
- General Synod of the Anglican Church of Canada: In Sure and Certain Hope, Taskforce on Physician Assisted Dying

#### 2. General:

- Dave Jacobs: Ministry to the Dying and their Families, (Facebook/Twitter) An interview with Bob Groth Lutheran pastor who has worked 10 years in hospice care/ night chaplain at his local hospital.
- Five Reminders as we Serve the Dying and their Families, Blog: Eternal Perspective Ministries
- Larry Yeagley: Ministering to the Families of the Terminally III
- Carole A Rayburn: Clinical and Pastoral Issues and Challenges in Working With the Dying and Their Families, Adultspan Journal, Volume 7, Issue 2 Fall 2008, pp 94-108. 23/12/2011
- Dr Sarah Bachelard: Resurrection and Moral Imagination, Ashgate 2014
- Kathryn Mannix: With the End in Mind, William Collins
- Dr Charlie Corke: Letting Go: How to Plan for a Good Death, Scribe
- A Prayer Book for Australia (Anglican Book of Common Prayer), Broughton Books 1999
- The Encyclopedia of Christianity http://books.google.com.au
- Bowman, G. W. & Koenig, H.G. (1997): Dying, Grieving, Faith and Family: A Pastoral Care Approach, NY: The Haworth Pastoral Press (Amazon.com)
- Davison, Andrew & Evans, Sioned: Care For the Dying: A Practical and Pastoral Guide, (Google Books).
- AIPC Article Library: Counselling the Terminally III
   https://www.aipc.net.au/articles/counselling-the-terminally-ill-anxiety-and-spirituality
   Grief and loss in a chronic illness setting.
- Grief/Loss/Death/Dying,

Psychoz Publications
<a href="https://www.psychotherapy.com.au">www.psychotherapy.com.au</a>
Bookstore, on-line training, journal

Rob Buckingham, Dying with Dignity, (Blog)
 17/10/2017
 http://baysidechurch.com.au/dyingwithdignity

- The Blackwell Companion to Christian Ethics, pp.379-380
- Carole Bailey Stoneking: Euthanasia, Suicide, Letting Die, Chapter 28, Receiving Communion).
- Michael Barbato: Caring For the Living and Dying, Text Publishers
- Endpaper 1 Summary of the Legislation, Victorian Government's Voluntary Assisted Dying Act 2017 Authorised Version 1 July 2019 See separate attachment