



IN SURE & CERTAIN HOPE

THEOLOGICAL AND PASTORAL RESOURCES
ON PHYSICIAN ASSISTED DYING

Study Guide



THE GENERAL SYNOD
OF THE ANGLICAN CHURCH OF CANADA



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PURPOSE OF THIS STUDY GUIDE

This Study Guide has been designed as a companion piece to the General Synod's resource entitled *In Sure and Certain Hope: Resources to Assist in Theological and Pastoral Response to Physician Assisted Dying*.

In Sure and Certain Hope was produced by a Task Force on Physician-Assisted Dying, reporting to the Faith, Worship, and Ministry Committee of General Synod. It was received by the Council of General Synod of 2016. It built upon previous work accomplished in 1998, that issued in the study resource, *Care in Dying*, considerations on euthanasia, and a guide to help in the creation of Advanced Care Directives for end-of-life decision making. We are aware that, as the years go by, from the time of

the 2016 change in federal law to allow for medical assistance in dying, that our Church will need to continue to reflect upon the experiences of those amongst us who choose such measures, those who choose not to request Medical Assistance in Dying (M.A.I.D.), and upon the experiences of those who journey with the dying in any situation. As such, this work is to be considered an open file and we invite feedback and the sharing of stories, questions, and insights. Please contact Eileen Scully, Director of Faith, Worship, and Ministry for further information (escully@national.anglican.ca; 416-924-9199 x286; 80 Hayden Street, Toronto, M4Y 3G2).

The study guide does not stand alone, but rather serves to help Canadian Anglicans use the primary resource (*In Sure and Certain Hope*) to reflect on and to talk about our pastoral responses to the changes that have taken place with regard to the legal framework governing medical assistance in dying.

In Sure and Certain Hope provides a number of resources to help guide and shape personal reflection and pastoral response. This study guide is intended to help individuals and groups to connect their stories, hopes, concerns, and questions to the more general framework provided by *In Sure and Certain Hope*. In this way we hope that the issues and ideas raised in that resource might come alive for people and prove to be of greater use in supporting appropriate pastoral care and loving responses to those making difficult decisions at the end of their lives. It is important to remember that *In Sure and Certain Hope* was not intended as a contribution to the debate about the moral appropriateness of medically-assisted dying. The changed legal landscape has moved us beyond that to a point where many of us are likely to know, love and care for those who will face difficult decisions and may choose to avail themselves of medically-assisted dying or to reject such an option. Either way,

we as Christians are called to care, and in order to do that more effectively we need to learn to speak together about these issues with greater depth, clarity, and charity. We need to learn to voice within community our hopes, concerns, fears, and faith in the face of death.

As Christians we are called to live as the Body of Christ, in communities of care. As such, we are bound to a duty of care for all who suffer, and all who are dying. The ministry of accompaniment, especially alongside the sick and dying, is not something that is only for professional caregivers. It is at the core of our common identity as expressed in our common baptism. We can only do this together. To do this will require that we address our discomfort with speaking about illness, suffering, and death, realities that we all share. It is only when we can face these realities that we can hear something of the gospel's promise of hope in the midst of loss, life even in the midst of death.



IN SURE AND CERTAIN HOPE – EXECUTIVE SUMMARY

This study guide is intended to be a companion piece to *In Sure and Certain Hope*. It is not a stand-alone guide and will be most helpful to those who have read the report of the task group. It is therefore important to begin with some clarity about the purposes of *In Sure and Certain Hope*: what it attempts to achieve, and what it does not.

In the first place, it is important to note that *In Sure and Certain Hope* is not intended to provide moral arguments for or against a decision to resort to medically-assisted dying. Many of those arguments have been rehearsed in the earlier document, *Care in Dying* (Anglican Church of Canada, 1998). While *Care in*

Dying was well-received, the tentative conclusions it reached were by no means universally accepted. If anything, the changes in medical technologies and therapies over the twenty years since its publication have not changed this situation within the Church, and beyond the Church, support for medically-assisted dying has grown. The Faith, Worship, and Ministry Committee of General Synod (FWM) agreed in 2013 that it was time to review *Care in Dying* in light of these changes. However, in the early stages of that review the Supreme Court ruled that medically-assisted death is constitutionally permissible for certain patients under certain conditions.

While some may wish to continue the debate, despite the low probability of shifting either public or legal opinion, the task group decided that the more urgent matter for the Church as a whole was how to respond to the pastoral challenges that the new legal situation would bring. What could be the theological rationale for providing pastoral support to people making difficult end-of-life decisions, especially when those providing the support may or may not agree with the decision made? It is this question that *In Sure and Certain Hope* seeks to address. Thus, while we recognize that some may wish to continue the debate, our contention is simply that pastoral care of the dying is not the place to do this. Further, all involved in pastoral care are going to find themselves caring, if not for the dying, then at least for their families, loved ones, and caregivers. How are we to shape care in this context?

In order to provide support in the range of challenges that now face pastoral caregivers, *In Sure and Certain Hope* is divided into five sections. The first four are intended to provide resources for thinking through the issues involved in providing appropriate pastoral care. The fifth provides resources that might be used to shape a ministry of prayer with the dying and those around them.

The first section addresses the theological issues involved and takes its starting point from the approaches found in *Care in Dying*. The intention is not to enter a debate with the argument's conclusions of the earlier report, but to ask how the approaches taken might speak to our very different context. In doing so it identifies several principles that underlie the approach of the whole document. They are:

- Centrality of the duty of care. The central claim of *Care in Dying* was the duty of care and the harm caused by abandonment. This remains the central claim, although its implications may be rather different in our current context.
- The recognition of the Christian vocation to be members of the societies of which they are a part, even when those societies do not in all respects reflect the values that either the Church or the individual Christians might hold.
- The recognition of the multiple roles that people of faith have in relationship to the wider society and the importance of drawing thoughtfully on the scriptural, theological, and liturgical traditions in ways that support each of these roles.
- The primacy of the exercise of conscience and the inevitability of disagreement, particularly concerning decisions on matters that are complex and do not relate in any simple and direct way to scriptural witness.

Following this, *In Sure and Certain Hope* reflects on the question of palliative care. This was important to the task group for a number of reasons. Early on the courts had dismissed the importance of palliative care, and the task group acknowledged that not all patients would see such care as a viable option. The task group accepted this as a description of the current situation, and further noted that even with the provision of the best possible palliative care, some patients would still seek medically-assisted death. Nonetheless it seemed to the group that, without

the provision of excellence in palliative care, the options before patients were being artificially and unhelpfully restricted. To understand how palliative care might be part of a spectrum of options that promise our presence to persons at the end of life, it was important to articulate the range of care that needs to be provided and provide some reflection on best possible contexts for such care.

In Sure and Certain Hope seeks to unpack the dynamics of the pastoral encounter itself. This is seen primarily as a context in which the presence and actions of the caregiver assist the patient in recognizing and responding to the presence and love of God in the particularities and challenges of their circumstance. Pastoral care is relational and as such bears witness to the inter-related nature of all life. While pastoral care might involve spiritual guidance, that guidance should not take the form of the imposition of the caregiver's views, but be facilitative. It should enable patients to clarify their own needs and the needs of those for whom they are often deeply worried. The aim should therefore be, in the pastoral relationship, through words, sacrament, sign, and ritual, to enable the patient to explore their own relationship to God and others and exercise their conscience in ways that are informed by this wider context.

Finally, we provide a range of definitions and references. Even those readers of *Care in Dying* who disagreed with its conclusions expressed gratitude for the clarity brought by the definitions. The discussion of medical care options appropriate to terminally-ill patients continues to generate misunderstanding and confusion. If individuals are to make good decisions that truly reflect who they are, and if those gathered around them are to understand their decisions, we need to be able to communicate clearly and accurately. We hope that the updating of these definitions to reflect medical and legal and

social changes in our society will continue to support such communication.

The task group had a variety of positions regarding the Supreme Court ruling. We were, however, unanimous in our concern for the degree to which the language of the ruling isolated patients making such decisions from the significant others who were accompanying them in their illness and would be affected by their decisions. In no way did we wish to undermine the ethical importance of autonomy, but as people of faith, we recognize that individuals are born to live amongst and die in community. We express that hope that in the document *In Sure and Certain Hope*, and this study resource may together contribute to our capacity to sustain community in the darkest and most difficult parts of human living and dying.

With that in mind, we are providing some resources here to assist you in engaging with the content of *In Sure and Certain Hope*. These materials are not intended to lead you to agree with the approaches taken in that report, but rather to help you see how your response to the range of issues raised there can form a rich background to your own thinking and practise in what is a complex and difficult pastoral context for all of us.



WHERE TO USE IN SURE AND CERTAIN HOPE

Group discussion guided by *In Sure and Certain Hope* can be appropriate in many contexts including, for example:

- Small groups in parishes – whether existing study groups, ACW, adult Christian education forums or within specially-convened occasions
- Parish pastoral care teams
- Christian health care professionals
- Health care spiritual care providers
- Pastoral training programs

- Clergy and lay leader conferences
- Theological colleges and local training programs
- Families

In whatever context the discussion takes place, our experience suggests that mixed groups produce richer conversation than homogenous groups. Do consider inviting outside voices with particular experience or expertise that might be helpful to your group. Remember that the purpose is not to come to a decision but to support practices of love, care, and inclusion for those affected by decisions at the end of life. Above all, ensure that those who lead these conversations are properly prepared for what are often demanding and emotionally-draining discussions.



NOTES FOR GROUP LEADERS

Who should lead the conversation?

The leadership required for facilitated conversations about medical assistance in dying is a very particular sort of leadership. There may be reasons why, for example, it may not be the parish pastor, other clergy, or the best teacher in the parish who is best-suited to serve in this role. The person must primarily be a good listener and facilitator of discussion. Here are some of the qualities needed in a leader for these processes:

- facilitation skills: these are to be conversation sessions, in which the learning happens through exchange of stories and reflection on stories, rather than a lecture session

- personal maturity and experience of depth reflection on his or her own experiences with death, and the ability to differentiate own experience from the present conversation in order to serve as leader
- ability to pay deep attention to the process of conversation, to not allow injustices to happen in the group (some dominating, others silenced)
- has the time to commit to preparation, including of resources and of participants, as well as self-preparation, and to commit to follow-up with participants
- isn't alone, doesn't work alone, and has a supportive team outside of the conversation circle
- has strength and sensitivity of character to keep the group within norms of behaviour and focus
- doesn't have a personal stake in converting participants to a particular moral judgment about a theoretical position, but rather is committed to mutual engagement and learning and support.

How should a leader prepare?

A leader is responsible for gathering, preparing, supporting, and following through with the group work. It's not a simple matter of showing up for a one-time or several-session set of time, but is more like a continuum of care.

- *First, do the work yourself.* Even better, gather a peer group, perhaps others who will be leading conversations in their own contexts. Review the qualities desired in leaders, above, and check yourself in each. Dig into the Case Studies and call to mind your own experiences with death. How do you think of your own death? What care do you want?
- *Take care* in making invitations. Be clear about what the intentions and aims of *In Sure and Certain Hope* are. If those

whose desire for a debate about the yes or no of medically-assisted dying are indicating that this is their principal hope for a study session, find ways to redirect those desires into another forum – one which would be equally legitimate, but would require a different set of resources.

- *Get to know* the people who will be participating. Take the time to converse with them, to get to know a bit about their present, past, or anticipated connections in the realities involved.
- *Be clear* about the aims of the session(s). If there is a hoped-for outcome that involves action, name that up front. (Such could be development of a trained pastoral team in the parish, or mobilizing to do advocacy for better palliative care.)
- *Provide the print resources* and any other supports well ahead of time.
- *Invite more resources* from participants – some may have access to materials that we and you don't know about.
- *Prepare the space.* Comfortable space, lighting, temperature should all contribute to the comfort of the participants.
- *Review Suggested Norms for Group Conversations*, on page 25.

Resource people

Another important aspect of serving as a leader in this context is to identify others who can accompany the group. Do you know of others in your community whose particular skills, experiences, and personal qualities would be of assistance in support of the work? These might include people such as:

- the parish clergy and lay leadership, both to accompany, to participate, and to be present pastorally in the long range
- health care chaplains or spiritual care providers in a facility frequented by members of the parish or group

- grief counsellors from a local agency (often these can be found through hospital chaplains and sometimes through good funeral homes)
- someone who can plan and lead prayers and worship
- Remember to include resource people such as medical practitioners, social workers, and facilitators of difficult conversations, who can be of support to you as the leader.



SUGGESTED PROCESSES FOR DISCUSSION GROUPS

Review the notes for leaders (above) and pay attention to what needs to be done ahead of time. The importance of preparation cannot be overstated. Participants need to see an agenda in advance, to have a clear sense of what the event is about and what it is not about, and to have resources available for reading.

Here are some suggestions for ways to get into the substance of *In Sure and Certain Hope* and to lead conversations and learning events. The suggested process presumes one long event. The process can be adapted easily into several sessions. (See *Adapting the Process*, below.)

Gathering:

- The group – whether a large room full of clergy in a conference, or a small group of parishioners – needs to be gathered in the One who loves and reconciles us. Our communion in Christ is the vessel in which we live, and in which we undertake this work of study and holy conversation. We need these reminders by enacting prayer, worship, and silence.
- Introduction to the event by one who is serving in a 'convening' role (may be facilitator, may be someone else) – going through the agenda, the 'why' of the gathering, and making key introductions.
- Review of group norms for holy conversation
- Small group introductions – participants in small groups are invited to tell each other their names and something important about themselves, in a non-heavy ice-breaking self-introduction. Such a process may be invited with a neutral inviting question such as sharing something they loved from the place where they grew up, for example.

Story:

- Read one of the Case Studies, out loud, up to three times, with different voices, as follows:
- First time reading: Invite reflection on the story with the following:
 - As you witness this story, where do you find yourself resonating with the scene in front of you?
- Second time reading: Invite reflection on the story with the following:
 - Imagine yourself as the principle caregiver. Where do you find yourself resonating with the scene in front of you?

- Third time reading: Invite reflection on the story with the following:
 - Imagine yourself as the dying person. Where do you find yourself resonating with the scene in front of you?

(Note: “resonate” is neither a positive nor a negative reaction... it is simply about feeling a connection to the character. That can be a resonance of familiarity, or of discomfort, of any sort of emotion, or of questions.)

Reflections:

- Re-read, or present a synopsis of theological themes in *In Sure and Certain Hope* (these could be two, or several or many, depending upon the duration of the study process), such as the sections on personhood and community, dignity, or hope (Section I).
- Invite reflections: how do these theological principles connect with the experiences told in the stories?
- Invite deeper reflection: where does my experience resonate with what we are hearing?

Personal action:

- As a way of closing this part of the session, it might be a good idea to invite a small symbolic action on the part of participants. An example of such might be to ask each person to write a prayer on a piece of paper, and to place those pieces of prayer into an offering basket.

Break (Extremely important!)

Reconvening into Conversation Questions:

- Begin by reminding participants where you all are together in the process. Invite a time of silence and then prayer for them to help to re-centre.
- Pose a question to the small group(s) that invites participants to think about our own Christian presence with the dying, in this recently changed legal situation. Deal with only one question at a time, and provide time for participants to write some reflections before going into conversation. When beginning the conversation, it might be good to remind participants of the norms for conversation. Here are some examples:
 - What does it mean to me to “be present” to someone who is dying, and to “provide care”? What care do I want to experience when I am dying? What sort of presence?
 - Can I provide care for somebody who has very different values from mine? When I do this, how do my values relate to the values of the patient? What matters most?
 - What is the difference between providing moral arguments, on the one hand, and being present to somebody making this sort of moral decision? Can we do one without doing the other?
 - How would I describe the theological motivations for my pastoral care? What images would I use to articulate this role? Can I describe an occasion when those motivations came into conflict with other theological commitments I might have? How did I resolve the conflict?

Closing:

Be sure to keep time during the conversation in such a way that participants each have a minute or so to express a lasting impression or question in a final go-around. Close the session with prayer.

If this is a multi-session event, remind the group that they will be able to pick up the conversation in the next session.

It will be helpful to have some sort of closing action in addition to the prayer. This could be done using the written-prayer collection as in the beginning, or some other expression of raising one's questions and thoughts and feelings to be entrusted into God's care. Remind participants to make sure that they have someone to talk with before the next session comes around.



ADAPTING THE PROCESS

Keep the same general outline, with breaks and prayers and silence as appropriate:

- Gathering
- Story with imagining questions
- Reflections
- Closing

Work on your own, or better, with a leadership team, through the sections of *In Sure and Certain Hope* on theological issues, pastoral care, and palliative care, highlight three or four topical sections (according to how many sessions there are in your process), that might form a focus for each session.

It might be helpful to use the same case study or studies, along with the imagining questions, repeated across sessions, to encourage the unfolding of new questions and perspectives.

Don't try to overload too much content into each shorter session. One conversation question for each session could be enough.



SUGGESTED NORMS FOR HOLY CONVERSATIONS

It will be important to create a comfortable and safe space for the group's conversation. In setting norms, you are asking participants to name what they think they will need from others in order to feel able to fully participate in the discussions.

Some basics:

- Arrive on time for gatherings, start on time, and remain in the meeting as much as possible
- Be present: listen, engage
- No phones or other devices that can distract from the gathering

- Devote the allocated time for the topics. Respect the agenda
- Listen for and be open to the Spirit in the room

Strive to live the values of mutual hospitality:

- Encourage openness and honesty with the mutual respect that makes openness possible
- Listen actively, with attentiveness and respect, not rushing to react or respond. Sit with what you hear. Be caring and concerned and show it in the way that you listen.
- Acknowledge that individuals are a part of community in different ways
- Presume the good will of all present
- Respect each person in the circle, and be attentive to the gifts that each brings, especially those that are different from your own
- Listen carefully to others with personal intent. Respect different perspectives and try to learn from a perspective different from your own.
- Allow and encourage everyone to have a say, while nurturing the minority voice. Do not allow others to dominate, and check the quantity of your own contributions
- Be mindful of silence and don't rush to fill it
- Respect the sensitivity of certain information, and provide confidentiality when sought

Concerning Process:

- When necessary, give more time for a topic, aware that time limits sometimes produce bad processes. At the same time, be careful with time – don't schedule the

agenda so tightly that the necessary flexibility can't be exercised.

- Ground the work in prayer, expecting God's grace to be present with you

The leader should ask if the group has any questions, additions, or amendments to offer in order to make this list work for them. Make sure that you have everyone's agreement to abide by the norms and that you, as their facilitator, or any member of the group can remind people of their agreement to follow the norms should it become necessary.



CASE STUDIES: DIFFICULT CONVERSATIONS, SACRED LISTENING

CASE STUDY #1

The patient, John, is an 87-year-old male who was admitted to hospital after a fall in his home. John lived alone and was discovered on the floor by his personal care worker. It is thought he was on the floor for at least twenty-four hours. John was brought to the hospital emergency. It was soon noted on the chart that the patient seemed unhappy or depressed and was not inclined to much communication. It was also noted how under-nourished the patient was. At first it was assumed he was an

isolated and depressed person who had no family, but a loving family of nieces and nephews appeared.

Following a successful surgery on his hip, the patient contracted pneumonia. The pneumonia soon cleared but John continued to breathe with difficulty. He was also having difficulty swallowing food and was running the risk of choking on it. It was not known whether this was a long term problem or part of the recent trauma and pneumonia. John did not feel able to eat much of the liquefied food or drinks provided. He had no energy and the struggle to breathe didn't help. He told the doctor he was ready to die, that he didn't want to suffer any more, and requested physician-assisted dying. His family supported his decision.

After his recovery from the surgery and pneumonia, John began to give the doctors a little more information. John said he was so under-weight and under-nourished because he had been cursed by his neighbour who was a demon. The geriatric psychiatrist let everyone on the team know that such beliefs did not negate the patient's ability to make a medical decision. John was also getting weaker, though the reason was unknown. The medical team thought that a feeding tube might help with the nourishment issue. They hoped this would also give them time to find out why the patient was so ill and possibly treat him. John said to go ahead with the feeding tube, if that was what they wanted to do, but he still wanted assisted dying. He wanted to end all this suffering.

The medical staff told him they would rather have his permission. The family was very concerned that their uncle should have the care he wanted. The medical team needed to know John was suffering in the process of dying as well as a diagnosis in order to make a judgment about his eligibility for assisted death. Time was needed. The staff doctor was very upset

that he was actually looking for a reason to assist someone to their death.

The patient had mentioned God a few times so the chaplain was called in to see the patient. And to do "something". The staff doctor told the chaplain the patient's story in the hall outside John's room, with his voice rising anxiously for many to hear as he explained about the demons and searching for a reason to provide assisted death. One of the people who overheard everything later introduced herself to the chaplain as John's personal support worker. The chaplain and the doctor went into the room to speak with John together.

CASE STUDY #2

Hakim is a lay pastoral visitor in the parish. He visits Marie-Hélène (also a parishioner) on a weekly basis. They spend time discussing politics, parish news and, as Hakim puts it, “the meaning of life”. Marie-Hélène is critically ill and dying. She has a community-based palliative care team who supports her with daily visits, personal physical care, and medical supervision of her pain medicine. While relatively pain-free, she is bedridden. Her children live far away and visit as often as they can. However, she is dependent upon friends for emotional support and companionship.

Lately all she talks about is wishing someone would help her die and she wonders why God lets her suffer so.

Hakim has explored these thoughts with her. He understands she is struggling to find purpose and quality in her life. She argues that her world is getting smaller and in a sense, darker.

She finally asks Hakim to discuss with her his feelings and thoughts regarding assisted dying. They had both shared their faith stories over the months he had been visiting.

She still has some reservations. Is this a realistic choice? Is she betraying her faith by seeking out assisted dying? She understands the process involved and her palliative care physician is supportive of her right to engage assisted death. However, she finds that the palliative care team is sometimes too supportive and would appreciate a good, thorough conversation which would explore all of the dimensions of this life-ending decision.

Hakim admires Marie-Hélène and wants to be of assistance.

However, his lay pastoral care team has never discussed medically-assisted death and their pastor has never raised the issue within the congregation.

He wonders what he believes, and has anxiety about entering into this conversation with Marie-Hélène.

* * *

In the end:

This is the opportunity to wrap up the session and help people make the transition out of the group and its discussion. Take time for prayer, reflection, and the identification of what's been learned, or what was of value to people in the session. Thank participants for their contributions to the discussion.



NOTE REGARDING ADDITIONAL RESOURCES

Please see www.anglican.ca/..... for additional resources that may be of assistance as you work with *In Sure and Certain Hope*, and more broadly with these matters. Check frequently, as these pages will be updated regularly based on what we are able to create and to find, and based on feedback from discussion groups.

At this time of writing, it has been a bit more than a year since medical assistance in dying has been employed in Canada. Those who provide pastoral care as parish leaders and as hospital spiritual care providers are only now starting to be able to reflect on experiences of the ministry of presence at death. Pastoral

response and presence with the loved ones and the dying who have chosen medical assistance in death is still a new thing to be absorbed and reflected upon. Ritual needs at the end of life, in a context of medically-assisted death, are only just now able to be considered.

If we as the Church are to be as fully present as we can be, we need to share our stories. The creation of suggested ritual design, and guidance about the sorts of pastoral care needs for the dying in the hastened experience of death, as well as for the communities of love and care around the dying require deep reflection in this new context.

More importantly, the fact itself of choice and decision requires a self-consciously new pastoral approach to care for the dying. The context alone can create extreme stress for the dying and for caregivers as well. In irremediable pain, how is one to make any sort of decision? Pastoral response demands calm and the sort of presence that does not increase the stress and therefore the pain. What is it to be the presence of God's grace in these contexts?

As we continue to pay attention these complex realities, Anglican leaders need to share with each other our experiences and reflections. Please help us to continue to offer a place to facilitate conversation and the creation of new resources by sending us anonymous notes from any study and discussion sessions that you lead.



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