The BABEL Approach to Advance Care Planning

Workbook for Team Members in Long-Term Care

This information sheet is based on research funded by the Canadian Frailty Network and Research Manitoba. © A. Garland, G. Heckman, and BABEL Long-term Care Investigators. All rights reserved. Permission to reprint only in its entirety and only for non-commercial use. For more information about the research visit the-ria.ca/research/research-projects/babel
Table of Contents

SECTION 1: Overview .................................................................................................................. 3

SECTION 2: The “Weak Links” In Advance Care Planning ......................................................... 4

SECTION 3: Conducting ACP Discussions .................................................................................. 5

SECTION 4: Assessing Residents’ Capacity To Make Their Own Medical Decisions .......... 6

SECTION 5: The Preliminary BABEL ACP Discussion ............................................................... 6
  About the preliminary BABEL ACP discussion ................................................................. 6
  Preparing for the preliminary BABEL ACP discussion ...................................................... 7

SECTION 6: Scripts for the Preliminary ACP Discussion .......................................................... 8
  SCRIPT 6A. Introductions and state the purpose of preliminary ACP discussion ............... 9
  SCRIPT 6B. Confirm the SDM ............................................................................................. 9
  SCRIPT 6C. Address preliminary preferences related to CPR/resuscitation ................. 10
  SCRIPT 6D. Address preliminary preferences for emergency room and hospital transfers 12
  SCRIPT 6E. Conclude, and arrange the follow-up full BABEL ACP discussion ............. 13

SECTION 7: The Full BABEL ACP Discussion ........................................................................... 15
  About the full BABEL ACP discussion ............................................................................ 15
  Preparing for the full BABEL ACP discussion ............................................................... 15
  Identify medical emergencies that the resident is most likely to experience ................. 16

SECTION 8: Scripts for the Full BABEL ACP Discussion .......................................................... 19
  SCRIPT 8A. Confirm the identity and role of the SDM ....................................................... 20
  SCRIPT 8B. Prepare the SDM for emergencies ................................................................. 21
  SCRIPT 8C. Review the resident’s current clinical situation and prognosis ................. 22
  SCRIPT 8D. Explain the main alternative philosophical approaches to care ................ 23
  SCRIPT 8E. Address the range of medical options specific for the resident ................. 26
  SCRIPT 8F: Conclude the discussion ............................................................................. 29

SECTION 9: Additional Scripts for Specific Clinical Situations ................................................ 30
  SCRIPT 9A. Antibiotics for pneumonia in residents with advanced neurologic disorders 30
  SCRIPT 9B. Care of advancing heart failure ..................................................................... 33
  SCRIPT 9C. Use of artificial feeding tubes ....................................................................... 35
  SCRIPT 9D. Permanent/long-term use of artificial hydration (intravenous or subcutaneous fluids) 39

SECTION 10: Info to Support ACP Discussions in Other Clinical Situations ......................... 42
  10A. Chronic Obstructive Pulmonary Disease (COPD) .................................................. 42
  10B. Kidney dialysis ......................................................................................................... 43
  10C. Diabetes management ............................................................................................... 44
  10D. Stopping medications (deprescribing) .................................................................... 45

SECTION 11: Clinical Outcome Diagrams .................................................................................. 46

SECTION 12: The BABEL ACP Pre-Discussion Guide for Long-Term Care Team Members .... 47

SECTION 13: The BABEL ACP Pre-Discussion Guide for Physicians & Nurse Practitioners .... 49

SECTION 14: Checklist for the Full BABEL ACP Discussion .................................................. 52
SECTION 1
Overview

What is advanced care planning?

Advance care planning (ACP) is a set of processes that help people think about, talk about, and document their wishes for healthcare in the event they become unable to speak for themselves. It includes designating substitute decision makers (SDMs) who will represent residents’ interests and wishes if and only if residents cannot speak for themselves.

What is the BABEL Approach to Advance Care Planning?

The BABEL Approach to Advance Care Planning (BABEL ACP) provides communication tools to long-term care (LTC) team members to support ACP conversations with a focus on each resident’s needs and wishes. BABEL ACP can be used as a standalone approach to ACP or to complement other approaches by helping LTC team members better tailor conversations around the health outcomes most likely to be experienced by a resident. BABEL ACP is informed by research, best practices and extensive experience in ACP; it emerged through a research study called “Better tArgeting, Better outcomes for frail ELDerly patients”. You can read more about the BABEL research project on the Schlegel-UW Research Institute for Aging website.

BABEL ACP considers the unique medical situation of each resident, and recognizes the individual needs, preferences and goals of residents. It was designed to support clinicians, residents, and their SDMs in navigating the difficult and stressful decision-making that arises when residents have health emergencies.

BABEL ACP can be used with all LTC residents but is particularly recommended for those with characteristics indicating a high chance of having a major medical event within the next 6–12 months. These characteristics can be obtained from the routinely available assessments done in many LTC homes around the world, using the Resident Assessment Instrument (RAI, also called interRAI or MDS). Such characteristics include a CHESS (Changes in Health, End-stage disease and Symptoms and Signs) score of 3 or greater, leaving more than 25% of food uneaten, and/or the presence of heart failure or cancer. Alternative high-risk characteristics can be substituted for these specific ones.

What is included in this workbook?

This workbook includes details of two separate kinds of ACP discussions:

1. The preliminary BABEL ACP discussion should occur soon after a resident moves into LTC and aims to clarify initial wishes regarding resuscitation and hospitalization. This is a brief conversation and takes about 20–30 minutes.

2. The full BABEL ACP discussion should ideally occur 2–6 weeks following the preliminary discussion and includes clarifying the current medical situation, prognosis, preferred philosophy of care, and realistically achievable wishes regarding specific medical options. Thereafter, it can be repeated yearly, and if the resident has a change in clinical status.

A key feature of BABEL ACP is SCRIPTS which provide suggested language to deliver information to residents and their families. They should be viewed as suggestions on how to incorporate best practices into ACP discussions.
SECTION 2

The “Weak Links” In Advance Care Planning

The following are common problems in ACP that can lead to residents receiving medical care that is not what they had wished to get. BABEL ACP aims to address and eliminate these issues.

PROBLEM 1: The identity of the SDM is unclear
1. No SDM has been designated.
2. A designated SDM is unaware they are a designated SDM.
3. A designated SDM is unprepared or reluctant to assume the SDM role.
4. Confusion or conflict occurs because other family or friends are either unaware that the SDM has been chosen or challenge the legitimacy of the designated SDM(s).

PROBLEM 2: The SDM role is poorly understood by SDMs and team members
1. Elderly and frail LTC residents are often assumed by LTC team members to be incapable of providing any input into their care, and thus are not fully consulted, or may even be completely excluded from discussions related to treatment wishes and choices. As such, team members may think that they only need to consult the SDM, when in fact the resident should be consulted to the fullest extent that they are able.
2. The SDM is unaware of the resident’s preferences and wishes.
3. The SDM cannot or does not separate their own preferences and wishes from those of the resident.

PROBLEM 3: Insufficient information is provided to the resident and SDM ahead of a health emergency, in relation to:
1. The resident’s most likely medical course (prognosis).
2. When end-stage disease is present—i.e., a disease in an advanced stage and for which disease-modifying treatment options are very limited or do not exist.
3. Expected benefits/potential harms of specific care interventions and medical treatments.
4. The extent to which the LTC home is able to address future medical challenges or symptoms without having to transfer the resident to the emergency room or hospital.

PROBLEM 4: Information and reassurance is not adequately provided to residents and SDMs during a health emergency:
1. Team members are unable to find and/or access documentation about previously expressed ACP wishes.
2. Residents and SDMs do not understand that some treatments, as well as effective symptom and pain management, can be provided in the LTC home.
3. Team members struggle to convey clinical information that may be uncertain, while also ensuring that the resident and SDM recognize that the LTC home team is competent.
4. Team members do not remind the SDM of the resident’s care wishes, or reassure the SDM that the care desired by the resident can (in many but not all cases) be provided in the LTC home.
Conducting ACP Discussions

A well-conducted ACP discussion ensures that care provided reflects the wishes and preferences of the resident. The following suggestions are intended to support LTC team members performing this task.

1. All medical care should be based on the resident’s values and wishes regarding their care, combined with an understanding of what is realistically achievable for their specific medical situation. While it is the team member’s job to explain the true medical situation, it is not their role to try to sway or persuade the resident into accepting a particular course of action.

2. LTC team members who are leading ACP discussions should review this entire workbook ahead of time. Other LTC team members that are involved (but not leading) the discussions should review the BABEL ACP Pre-Discussion Guide for Team Members in Section 12.

3. Before conducting ACP discussions, the LTC team should meet to ensure that they have a clear and shared understanding of the resident’s clinical situation, and of the likely potential trajectories and outcomes that can be expected for the resident. While it is never possible to predict exactly what happens to individuals, the ability of the care team to answer relevant clinical questions instills confidence in the team among residents and SDMs.

4. ACP discussions are best arranged and organized in advance.

5. ACP discussions should be held in a quiet, private, and comfortable location.

6. ACP discussions should ideally be inclusive and involve everyone the resident would want to attend, or who has insight into the resident’s end-of-life wishes (i.e., not just the SDM).

7. Where possible, it is preferable that the SDM(s) are present in person.

8. Team members should primarily speak with the resident unless the resident is completely unable to participate in the discussion. Keep in mind that residents may still be able to participate and communicate their wishes even if they are nonverbal.

9. Team members should use simple language (aim for a Grade 8 level), and avoid using jargon or medical abbreviations. For example: say heart failure, not CHF; say breathing machine not ventilator; say insert a breathing tube not intubation. It is the team members’ job to make sure that residents and SDM(s) understand what is being said. Make sure to pause periodically to ask if everyone understood what was said.

10. When possible, have a certified medical translator present. Family members acting as translators may not accurately represent what has been said.

11. Be sensitive to the possible presence of underlying family conflict that may cause the resident to feel coerced into expressing specific care wishes. LTC team members should carefully observe resident and family/SDM interactions, watching for language, signs, or body language that suggest that the voice of the resident is being stifled or coerced. The LTC team may choose to discreetly explore these dynamics and spend more time to better understand the resident’s wishes, and to assess which family members demonstrate alignment and respect for these, and who could thus be suitable SDMs.
SECTION 4
Assessing Residents’ Capacity to Make Their Own Medical Decisions

Decision-making capacity refers to a person’s ability to understand and make known their wishes regarding medical care. This includes the ability to consent to and refuse medical treatments.

Capacity can change over time (i.e., worsen with stroke or fluctuate with delirium). **Capacity is specific to a single medical care issue at a specific time.** A person can have capacity for some simpler care issues (e.g., influenza vaccination), but not for others (e.g., artificial life support).

Therefore, except when a resident has permanent and severe cognitive disability (such as severe dementia, persistent coma, vegetative state, or is completely unable to communicate), it is necessary to assess a resident’s capacity for all expressed care wishes and treatment choices.

In BABEL ACP, **assessing capacity is integrated into the discussions.** Capacity is based on whether the LTC team members leading the discussion and the SDMs judge that residents understand and appear to be making rational choices consistent with their beliefs and philosophy.

After key steps, pause and ask the resident to share their understanding of the discussion that just occurred. If the resident’s responses are coherent, then conclude they have capacity. Remember that even if they aren’t fully capable, it is still often possible for the resident to express what is important to them, their philosophy of life, and any end-of-life preferences.

1. The purposes of this discussion are: (i) to determine the resident’s wishes regarding who will be their SDM; (ii) to begin the discussion about resuscitation (CPR); (iii) to begin the discussion about when/why the resident may wish to be transferred to the emergency room or hospital; and (iv) to arrange a follow-up meeting for the full BABEL ACP discussion and provide the resident with BABEL ACP materials to review in advance of the full discussion.

2. The preliminary BABEL ACP discussion is meant to address these four areas but without the complete medical and philosophical context included in the subsequent full BABEL ACP discussion. It is important to understand these areas soon after a resident enters the LTC home.

3. Thoughts/wishes from this discussion will be revisited during the full BABEL ACP discussion.

4. The preliminary BABEL ACP discussion should be used with residents newly admitted to the LTC home and occur as soon as possible after admission (ideally within the first few days but at most within one week).
Preparing for the preliminary BABEL ACP discussion

The following tasks should be completed by the LTC team member who will be leading the preliminary BABEL ACP discussion.

1. Arrange a date and time for the preliminary BABEL ACP discussion; this meeting should be in-person and should include the resident, SDM(s) if they have been chosen, and other family or friends who the resident (or SDM) wants present.
   a. Tell the resident and other participants that the purpose of the meeting is to BEGIN talking about the resident’s wishes for care while they are living in the LTC home.
   b. Let everyone know in advance that this meeting should take about 20–30 minutes.
   c. If possible, the resident’s LTC physician should participate in this discussion.

2. Determine whether an SDM has already been designated, can be contacted, and is available for the discussion. Keep in mind that a resident can have more than one SDM.

3. Identify and review existing documentation related to previously expressed ACP preferences.

4. Provide all LTC team members who will be involved in the preliminary BABEL ACP discussion with a copy of the BABEL ACP Pre-Discussion Guide for Team Members (Section 12).

5. Confirm whether the resident’s LTC physician will be present at the preliminary BABEL ACP discussion; if yes, provide them with a copy of the BABEL ACP Pre-Discussion Guide for Physicians and Nurse Practitioners (Section 13). Ensure that any nurse practitioners attending the meeting also receive a copy of this guide in advance.

6. Arrange a huddle with the LTC team (including the physician, if available) to prepare for the preliminary BABEL ACP discussion. During this huddle, the team member who will be leading the preliminary BABEL ACP discussion should:
   a. Remind the team about BABEL ACP and ensure that they have reviewed the BABEL ACP Pre-Discussion Guide for Team members (Section 12).
   b. Ensure that the team has a shared understanding of the resident’s clinical status, likely clinical trajectory, and outcomes. This includes reviewing the resident’s diagnoses.
   c. Review any documentation of prior ACP discussions and expressed wishes.
SECTION 6
Scripts for the Preliminary ACP Discussion

This section contains the five scripts of the preliminary BABEL ACP discussion. These scripts are intended to support LTC team members to have discussions with residents and their SDM(s) about their ACP wishes. Residents may choose to include their care partners, family members and/or other loved ones in the conversation.

IMPORTANT

All statements and questions in the scripts below are meant to be directed at the RESIDENT, not the SDM(s) or other participants, unless the resident is completely unable to participate in the conversation, or there is a specific note in the script that the question or comment is directed at the SDM(s). For example, if a script says “you”, it is referring to “you, the resident”. As such, it is important that the LTC team member(s) who are leading the discussions both face the resident, and speak directly to the resident. After all, it is the residents’ wishes that we need to understand and honour, rather than other peoples’ wishes for them. That being said, the SDM(s) should be included intermittently and can provide additional information or clarity as well as ask questions. If the resident is completely unable to participate in the conversation, the scripts may need to be altered slightly by the team member so that questions are directed at the SDM.

Remember that capacity assessment (i.e., determining whether a resident is capable of making a medical decision) is embedded within the discussion process (See Section 4). After key moments in the discussion, pause and ask the resident to share their understanding of the discussion that just occurred. If the resident’s responses are coherent, then conclude they have capacity. Remember that even if they aren’t fully capable, it is still usually possible for the resident to express what is important to them, their philosophy of life, and any end-of-life preferences.

A note about scripts

1. The boxes shaded in mauve provide information for team members, including context and prompts to direct the discussion.
2. The sections with bullets are suggested scripts.
SCRIPT 6A. Introductions and state the purpose of the preliminary ACP discussion

Notes for the Team Member
– This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.

Script
• Hello, my name is [team member name] and I am a [team member position].
• We are glad that you have invited people close to you to join us today, to provide help and support with the important topics that we will talk about.

Notes for the Team Member
– Have everyone introduce themselves.

Script Continued
• This should be a short discussion today, no more than 20–30 minutes.
• What we hope to do is begin to learn about you and your wishes about two key parts of medical care while here in the long-term care home.
• At the end of this discussion, we will hand out some materials to look over and arrange to have a follow-up meeting in a few weeks.
• At that follow-up meeting, we will have a better idea about your health, so we can better revisit the care wishes made known to us today and make additional ones that are needed.

Notes for the Team Member
– Answer any further questions as needed. Move onto Script 6B.

SCRIPT 6B. Confirm the SDM

Notes for the Team Member
– This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.

Script
• Now we want to confirm who you would like to speak for you, if you become unable to speak for yourself. The person you identify is called your substitute decision maker (also known as an SDM). You can also have more than one SDM.
Notes for the Team Member

– You will want to reference “The Role of the Substitute Decision Maker” BABEL ACP handout with the resident and their care partner, family and/or loved ones to help them make this decision.

– This decision may have already been made and documented prior to admission to the LTC home. If so, the goal of this part of the discussion is to confirm the choice of SDM(s) and review this role with all attendees.

– Even if an SDM has already been documented, it is important to continue with this script to ensure that everyone understands the role of the SDM.

Script Continued

• If a medical emergency occurs and you are unable to speak for yourself, it is important that your wishes are respected, and that the SDM commits to expressing your wishes for you.

• That’s why we need to have SDMs be part of these discussions, so that everyone is on the same page, understands the achievable goals, and knows what you would want if these medical situations arise.

• Have you identified who will be your SDM? If not, it will be necessary to think about who this would be.

Notes for the Team Member

– PAUSE.

– Open the conversation to the resident and the family.

– Ensure that the resident identifies the SDM(s), and that the SDM(s) accept this responsibility (if present).

– Though generally all goes well, LTC team members should still listen and watch closely for signs or body language that suggests possible coercion of the resident, or disagreement among family members. If so, be prepared to gently engage and attempt to address concerns and ensure a consensus that respects the resident. If disagreement arises, disrupts the meeting, and/or causes distress to the resident, consider stopping and rescheduling the meeting.

– Answer any further questions as needed. Move onto Script 6C.

SCRIPT 6C. Address preliminary preferences related to CPR/resuscitation

Notes for the Team Member

– This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.
Script

- Next, we want to talk about a specific medical emergency—if we find you without a heartbeat, or not breathing.
- When that happens to someone, unless we know that the person does not wish for it, we call an ambulance and perform resuscitation—CPR—where we push up and down on the chest to try and get the heart beating and give artificial breathing.
- Have you heard of CPR?

Notes for the Team Member

- PAUSE.
- Invite thoughts, and comments from the resident, SDM(s), and others in the group before moving on.
- Consider using the survival illustration for cardiac arrest in LTC homes (see Section 11).

Script Continued

- It is important to know about CPR because it’s not like on television. On TV, most people in this situation live, but in real life only about 3 in 100 long-term care residents who get CPR are alive 30 days later. While we cannot be certain what would happen to you, we do know that people who survive can end up being MORE disabled than they were before. Some suffer permanent brain injury.
- If you tell us that you do not wish to undergo CPR, we will make sure that you will be comfortable and will be able to pass away peacefully.
- In other words, if your heart stops, would you want it to be treated as a medical emergency and do CPR to try and get the heart restarted, or would you prefer to be allowed to pass away peacefully?

Notes for the Team Member

- Make sure to check that the resident and SDM(s) understand what cardiac arrest entails, that there IS a choice to perform CPR or not, and that these two choices have different implications. **This is done to check the resident’s capacity to understand information.** You may need to repeat or clarify information. You should ask the resident to explain their reasoning for the choice expressed. Discuss as needed.
- Be clear, direct, and give the resident and SDM time to understand and ask questions.
- If the resident appears to hesitate or not fully understand, make sure that the SDM and other family members at the meeting understand. Answer questions as needed.
- Ensure that the resident’s expressed wishes (or as expressed by the SDM if the resident is not able to) regarding CPR have been heard and understood.
- Clearly repeat what the resident indicated regarding CPR and resuscitation.
Script Continued

• So, if I understand correctly, if one of our nurses were to find you without a heartbeat or not breathing, you would prefer that we [REPEAT YOUR UNDERSTANDING OF THE RESIDENT’S WISHES ABOUT RESUSCITATION].

Notes for the Team Member

– Document the resident’s wishes regarding CPR/resuscitation in the resident’s chart.
– Answer any further questions as needed. Move onto Script 6D.
– If the resident has chosen to forego CPR and an Implanted Cardioverter Defibrillator (ICD) is present, it will need to be deactivated. Contact the resident’s cardiologist.

SCRIPT 6D. Address preliminary preferences for emergency room and hospital transfers

Notes for the Team Member

– This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.

Script

• We want to discuss what to do if you get sicker and need additional treatment. We want to know whether you would want to be transferred to the emergency room or hospital, or to stay here and get treated at the long-term care home.
• Unless we know otherwise, we will call an ambulance and send you to the emergency room or the hospital. But we will always ask about your preference for being transferred when it happens.
• Sometimes, going to the hospital is a good idea. Though many conditions can be treated in the long-term care home just as well, some treatments are only available in the hospital.
• For some long-term care home residents, certain hospital treatments (such as surgery, tubes, or dialysis), or just being in a different place, can cause more confusion and disability, and sometimes that is permanent.
• Talking about this now will provide us with a sense of your preferences.
• What are your thoughts about this? How would this fit with your wishes?
• In general, if you get sicker, would you wish to go to the hospital, or remain at the long-term care home and do what we can here?
Notes for the Team Member

- Be clear, direct, and give them time to understand the information and ask questions.
- If the resident appears to hesitate or not fully understand, make sure that the SDM(s) and other family members at the meeting understand. Answer questions as needed.
- Use “check back” (having the resident/SDM(s) explain in their own words) to assess their understanding of their clinical state and possible course.
- When the resident and/or the SDM(s) appear to have understood, summarize discussion results.
- Clearly repeat what the resident said about their wishes regarding being transferred to the emergency room or hospital:

Script Continued

• So, if I understand correctly, if you were to get sicker, your wish would be that we [REPEAT YOUR UNDERSTANDING OF THE RESIDENT’S WISHES ABOUT SUCH TRANSFERS].

Notes for the Team Member

- Document the resident’s wishes regarding acute transfers in the resident’s chart.
- Answer any further questions as needed. Move onto Script 6E.

SCRIPT 6E. Conclude, and arrange the follow-up full BABEL ACP discussion

Notes for the Team Member

- This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.
- The initial priorities of CPR and hospitalization have now been addressed. There may be other medical treatments that might be considered for this resident that also have implications on their quality of life and of end-of-life care.
- These will be discussed in detail in the subsequent full BABEL ACP discussion. For most residents, these issues do not require immediate attention on admission, but will need to be addressed sooner than later if the resident has characteristics that put them at a high risk of having a medical emergency soon.
- The LTC team should now call the meeting to a close, and ensure that the discussion is documented, including resident capacity and expressed wishes.
Script

• We have done what we needed to do today. We had a good meeting. Thank you all for coming.
• We addressed whether you would want to be hospitalized if things got worse, and what to do if your heart stops.
• Remember, this discussion is for you to express your wishes. If these decisions change, let us know.
• We still need to talk about your wishes regarding all other medical care issues that might arise in the future. To do that, we want to arrange to have another meeting in 2–6 weeks. At that meeting, we will have a better idea about your health, so we can better help regarding the wishes expressed today, and additional ones that still need to be addressed.

To help everyone get ready for that discussion, we have a few handouts to give you. Also, there are some other materials about advance care planning here in the long-term care home. One that many people find useful is the one called “Speak Up.”

Notes for the Team Member

– Hand out copies of the three short BABEL ACP handouts:
  a. What is Advance Care Planning?
  b. Different Philosophies of Care for Advance Care Planning
  c. The Role of the Substitute Decision Maker
– Show them where in the long-term care home they can obtain other materials on ACP.
– Provide the resident and SDM(s) with any other documentation that may be relevant to the specific diagnoses (e.g., heart failure, Parkinson’s disease).
– Make sure to document the date/time for the next ACP discussion. If there are still arrangements to be made for it, follow up on them as soon as possible.
– Document (be as specific as possible) whether, during this discussion, the resident had full, partial, OR lacked capacity for understanding/making their wishes known regarding medical care.
SECTION 7
The Full BABEL ACP Discussion

Make sure that you are familiar with the principles in Sections 3 and 4 before beginning this section.

About the full BABEL ACP discussion

1. When possible, this discussion should occur within 2–6 weeks after the preliminary BABEL ACP discussion. It should have been arranged at the end of the preliminary BABEL ACP discussion, or shortly thereafter.

2. If a preliminary ACP discussion did not occur, or occurred awhile ago, then arrange the full BABEL ACP discussion to happen as soon as possible.

3. The 5 objectives of the full BABEL ACP discussion are to:
   a. Ensure that the SDM understands and accepts their role.
   b. Prepare the SDM emotionally and intellectually for medical emergencies.
   c. Clarify the resident’s medical situation.
   d. Explain the alternative philosophical (“big picture”) approaches to care that exist.
   e. Explain the full range of medical options most relevant to the resident’s health, and understand their wishes regarding those options.

Preparing for the full BABEL ACP discussion. The following tasks should be completed by the LTC team member who will be leading the full BABEL ACP discussion.

1. Attempt to contact the resident’s family physician (usually different from the LTC physician) by phone. Let them know that an ACP discussion is going to take place in the LTC home and ask them to share relevant information about the resident and SDM, medical history, prognosis, and prior ACP discussions.

2. Arrange in advance to have the full BABEL ACP discussion in person. Seek to be inclusive by inviting the SDM and all relevant family, friends, spiritual advisors, or other trusted individuals, and the resident’s LTC physician. When arranging the meeting:
   a. Tell the resident and other participants that the purpose of the meeting is to continue prior discussions about the resident’s wishes for care while they are living in the LTC home. The meeting will discuss the full range of possible medical situations that might occur and identify the resident’s wishes for those situations.
   b. Let everyone know that the meeting may take 60 minutes or more.
   c. If possible, the resident’s LTC physician should participate in this discussion.

3. Provide the resident and SDM(s) with the three BABEL ACP handouts, if they did not already receive them:
   a. What is Advance Care Planning?
   b. Different Philosophies of Care for Advance Care Planning
   c. The Role of the Substitute Decision Maker

4. Direct the resident and SDM(s) to other ACP resources available for residents and their SDMs (e.g., the Speak Up booklet).
5. Identify and review existing documentation related to ACP preferences, including notes from the preliminary BABEL ACP discussion.

6. Provide all LTC team members who will be involved in the full BABEL ACP discussion with a copy of the BABEL ACP Pre-Discussion Guide for Team Members (Section 12).

7. Confirm whether the resident’s LTC physician will be present at the full BABEL ACP discussion; if yes, provide them with a copy of the BABEL ACP Pre-Discussion Guide for Physicians and Nurse Practitioners (Section 13). Ensure that any nurse practitioners attending the meeting also receive a copy of this guide in advance.

8. Arrange a huddle with the LTC team (including the physician, if available) to prepare for the full BABEL ACP discussion. During this huddle, the team member who will be leading the full BABEL ACP discussion should:

   a. Remind the team about BABEL ACP and ensure that they have reviewed the BABEL ACP Pre-Discussion Guide for Team Members (Section 12).

   b. Ensure that the team has a shared understanding of the resident’s clinical status, likely clinical trajectory, and outcomes. This includes reviewing the diagnoses that affect the resident.

   c. Review any documentation of prior ACP discussions and expressed wishes.

   d. Identify and be prepared to discuss the medical situations that are most likely to arise with this resident (see below). While it is mainly THOSE situations that are to be discussed, one of the aims of this discussion is to identify wishes regarding the following 6 items for all residents. These items are also included in the Checklist in Section 14.

   i. Antibiotics
   ii. Feeding tubes, if available and allowed in your LTC home
   iii. Transfers to the emergency room
   iv. Hospitalization
   v. CPR/resuscitation
   vi. The use of invasive mechanical ventilation

Identify medical emergencies that the resident is most likely to experience

1. A key part of the full BABEL ACP discussion is to explore the resident’s wishes regarding a range of medical issues and treatment options.

2. While it is not feasible to discuss every possible type of medical emergency that can occur, with knowledge of a given person’s medical situation, it is possible to predict the most likely ones. These most likely medical emergencies, and associated treatment options, are the main focus of the full BABEL ACP discussion.

3. Before this discussion, the LTC team member who will conduct it should become familiar with the resident’s specific medical situation, and the emergencies and medical options most likely to come up. To help familiarize themselves, the team member should contact the LTC physician who can provide them with information about the most likely medical emergencies.

4. Table A shows examples of medical situations that commonly arise in LTC residents, with additional information for specific clinical situations available in Sections 9 and 10. This list is not comprehensive—there are other medical situations that may arise that are not on this list.
5. In discussing any medical situation, it is extremely important to explain what the resident should expect of their physical and mental condition IF they survive treatment. This is vital, because we know that most people use this information to decide on their wishes about potential treatments.

6. People do not expect us to know for certain what will happen in their future, and we should not speak as if we do. It is OK to indicate the range of possible outcomes and to be realistic, but not act as if the only possibilities are death or full recovery. Many frail people survive with significant worsening of their physical or mental condition, and we must speak about that when appropriate.

Table A: Common Medical Emergencies That Occur in LTC Home

<table>
<thead>
<tr>
<th>URGENT SITUATION</th>
<th>COMMONLY OCCURS WITH</th>
<th>POSSIBLE TREATMENT OPTIONS</th>
</tr>
</thead>
</table>
| Infection        | • Almost any chronic disorder  
                     • Limited mobility  
                     • Frailty         | **Options available in LTC:** Oral antibiotics  
                     **Options requiring hospitalization:** Intravenous antibiotics |
| Pneumonia        | • Chronic obstructive pulmonary disease (COPD)  
                     • Other chronic lung problems  
                     • Cancer  
                     • Limited mobility  
                     • Frailty         | **Options available in LTC:** Supportive care; Oxygen  
                     Oral antibiotics  
                     **Options requiring hospitalization:** Intravenous antibiotics  
                     Non-invasive mechanical ventilation (e.g., CPAP, BiPAP)  
                     Artificial life support (invasive mechanical ventilation) |
| Aspiration       | • Neurologic disorders  
                     • Dementia  
                     • Frailty         | **Options available in LTC:** Oral antibiotics; Oxygen  
                     Feeding assistance; Diet modification  
                     Allow resident to eat, or accept that they will not  
                     Nasogastric feeding tube (short-term solution only)  
                     **Options requiring hospitalization:** Intravenous antibiotics  
                     Non-invasive ventilation  
                     Artificial life support (invasive mechanical ventilation)  
                     Surgically-inserted feeding tube (PEG/PEJ)  
                     Intravenous nutrition |
<table>
<thead>
<tr>
<th>URGENT SITUATION</th>
<th>COMMONLY OCCURS WITH</th>
<th>POSSIBLE TREATMENT OPTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Falls, fractures</td>
<td>• Advanced age</td>
<td>Options available in LTC:</td>
</tr>
<tr>
<td></td>
<td>• Osteoporosis</td>
<td>- Pain medicines; Splinting; Supportive care</td>
</tr>
<tr>
<td></td>
<td>• Neurologic disorders</td>
<td>Options requiring hospitalization:</td>
</tr>
<tr>
<td></td>
<td>• Dementia</td>
<td>- Intravenous pain medicines</td>
</tr>
<tr>
<td></td>
<td>• Frailty</td>
<td>- X-rays; Casting; Surgery (including for relief of severe pain)</td>
</tr>
<tr>
<td>Sudden weakness or numbness</td>
<td>• Stroke</td>
<td>Options available in LTC:</td>
</tr>
<tr>
<td></td>
<td>• Bleeding in brain</td>
<td>Options requiring hospitalization:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Brain imaging tests (e.g., CT or MRI)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Intravenous medications</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Surgery</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>• Any heart disorder (heart failure, ischemic heart disease, others)</td>
<td>Options available in LTC:</td>
</tr>
<tr>
<td></td>
<td>• Any lung disorder (COPD, asthma, others)</td>
<td>Options requiring hospitalization:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Intravenous medicines</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Non-invasive mechanical ventilation (e.g., CPAP, BiPAP)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Artificial life support (invasive mechanical ventilation)</td>
</tr>
<tr>
<td>Stops eating or unable to eat</td>
<td>• Advanced neurological disease (dementia, Parkinson’s disease, Multiple Sclerosis, Amyotrophic Lateral Sclerosis, Huntington’s disease, others)</td>
<td>Options available in LTC:</td>
</tr>
<tr>
<td></td>
<td>• Very near the end of life</td>
<td>Options requiring hospitalization:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Feeding assistance; Diet modification</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Allow resident to eat, or accept that they will not</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Nasogastric feeding tube (short-term solution only)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Intravenous administration of subcutaneous fluids</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Options requiring hospitalization:</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Surgically-inserted feeding tube (PEG/PEJ)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>- Intravenous nutrition</td>
</tr>
</tbody>
</table>
SECTION 8

Scripts for the full BABEL ACP discussion

This section contains the six scripts of the full BABEL ACP discussion. These scripts are intended to support LTC team members to have discussions with residents and their SDM(s) about their ACP wishes. Residents may wish to include their care partners, family members and/or other loved ones in the conversation.

IMPORTANT:

All statements and questions in the scripts below are meant to be directed at the RESIDENT, not the SDM(s) or other participants, unless the resident is completely unable to participate in the conversation, or there is a specific note in the script that the question or comment is directed at the SDM(s). For example, if a script says “you”, it is referring to “you, the resident”. As such, it is important that the LTC team member(s) who are leading the discussions both face the resident, and speak directly to the resident. After all, it is the residents’ wishes that we need to understand and honour, rather than other peoples’ wishes for them. That being said, the SDM(s) should be included intermittently and can provide additional information or clarity as well as ask questions. If the resident is completely unable to participate in the conversation, the scripts may need to be altered slightly by the team member so that questions are directed at the SDM.

Remember that capacity assessment (i.e., determining whether a resident is capable of making a medical decision) is embedded within the discussion process (See Section 4). After key moments in the discussion, pause and ask the resident to share their understanding of the discussion that just occurred. If the resident’s responses are coherent, then conclude they have capacity. Remember that even if they aren’t fully capable, it is still usually possible for the resident to express what is important to them, their philosophy of life, and any end-of-life preferences.

A note about scripts

1. The boxes shaded in mauve provide information for team members, including context and prompts to direct the discussion.
2. The sections with bullets are suggested scripts.
**SCRIPT 8A. Confirm the identity and role of the SDM**

**Notes for the Team Member**
- This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.

**Script**
- Hello, my name is [team member name] and I am a/the [team member position] here. We are here to learn more about your thoughts and wishes about medical care while you are here with us. We are glad that you have invited people close to you to help and give support with the important topics that we have to talk about.

**Notes for the Team Member**
- Have everyone introduce themselves.
- If you were successful in contacting the resident’s family physician before this first ACP discussion, mention that this was done.

**Script Continued**
- First, we want to confirm who you have chosen to speak for you, if you become too sick to speak for yourself. We call this the substitute decision maker.

**Notes for the Team Member**
- This decision may have already been made and documented prior to this discussion. You may refer to Script 6B for guidance. The goal is to confirm the SDM and review the role of the SDM.

**Script Continued**
- What we want to do now is make sure that everyone understands that the job of the substitute decision maker is to help us understand what you would wish for us to do, or not do, if you get too sick to tell us yourself.

- **It is critical to understand the job of the substitute decision maker**—it is to tell us what care you would wish to have done, NOT what the substitute decision maker would want done.

- If you become very ill and you are not able to tell us directly, we will provide the substitute decision maker with the best information on treatment choices, and how these might affect what matters to you.

- It is important that the substitute decision maker knows what you would want if a medical emergency arises, and respects your wishes when the time comes.

- That’s why we need to have the substitute decision maker be part of these discussions, so that everyone is on the same page, understands the achievable goals and wishes, and knows what you want depending on the medical situation.

**Notes for the Team Member**
- Ensure that the resident identifies the SDM, and that the SDM accepts this responsibility.

- Though generally all goes well, LTC team members should still listen and watch closely for signs or body language that may suggest possible coercion of the resident, or disagreement among family members. If so, be prepared to gently engage and attempt to address concerns and ensure a consensus that respects the resident. If disagreement arises and disrupts the meeting and causes distress to the resident, consider stopping and rescheduling the meeting.

- Answer any further questions as needed. Move onto Script 8B.
SCRIPT 8B. Prepare the SDM for emergencies

Notes for the Team Member

– Unlike all the other scripts, here you should speak mainly to the SDM, if present.

Script

• Now we want to talk about what substitute decision makers, like you, should expect if an emergency happens.

• Emergency situations DO happen, and [resident’s name] may then be too sick to decide about the treatment options. If that happens, a team member from the long-term care home will call you, and you will then have the responsibility of helping us to understand what [resident’s name] would want.

• Getting a phone call that a loved one is having a medical problem is scary. We help substitute decision makers like you through these conversations.

• We will ask you to get a pen and paper to write down notes and questions. We will do our best to answer those questions, and others that come up later. If desired, you or others can come to the long-term care home to talk with us in person.

• We will explain what has happened. We will also explain what could happen next. While we do not know what the future holds with absolute certainty, we will be able to help you know the range of things that could happen.

• We will remind you about any discussions that have been had with [resident’s name] related to their healthcare wishes.

• It is important for substitute decision makers like you to ask any questions to clarify what choices exist, and what to expect from each choice.

• We will ask you something like: “Based on your previous discussions with [resident name], and what you know about [their] values, beliefs, wishes and health, what would they want done – and NOT want done – in this situation?”

• If there is time, you may wish to speak to others for advice, but the final say on what treatments are used will come from your understanding of what [resident name] would wish for in the current situation.

• This conversation can be difficult, and we will help all we can.

Notes for the Team Member

– PAUSE.

– Invite thoughts, responses, and comments from the SDM, the resident, and others in the group.

– Document this discussion, being as specific as possible.

– Answer any further questions as needed. Move onto Script 8C.
SCRIPT 8C. Review the resident’s current clinical situation and prognosis

Notes for the Team Member
– This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.

Script
• Now, we want to make sure we are all on the same page regarding your current health status and medical situation.
• Will you please tell us your understanding about your current health?

Notes for the Team Member
– Have the resident (or SDM(s), if the resident is unable to do so) describe the current medical situation.
– Answer any questions. If the resident or SDM(s) (or others) are not completely clear about the resident’s medical situation, go over that medical situation. Use simple language, not medical jargon or abbreviations. This should be done by the physician or nurse practitioner if present.
– Remember that being able to provide you with a reasonably clear description of the situation is part of how to evaluate a resident’s capacity to understand and express informed wishes regarding medical care.

Script Continued
• Next, we want to make sure we all understand what your medical situation means in terms of your future.
• What do YOU think it means?

Notes for the Team Member
– Avoid using the word “prognosis.” Many people don’t understand this word. Instead, talk about “what the future holds for you” or something similar.
– Make sure that the resident and SDM(s) recognize the medical conditions present, such as heart failure, cancer, or neurological disorders, and conditions present that indicate a higher likelihood of a serious medical emergency in a shorter period of time [poor prognosis] (e.g., poor appetite).
– IF the resident is FRAIL, take time to explain that apart from specific medical disorders, frailty is related to shorter survival, a smaller chance to benefit from medical treatments, and a larger chance of experiencing complications from medical treatments.
– Answer any further questions as needed. Move onto Script 8D.
SCRIPT 8D. Explain the main alternative philosophical approaches to care

Notes for the Team Member
– This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.

Script

• Before we go on and talk about specific medical treatments, we want to explain the general types of approaches to medical care. We can call this the different “philosophies of care” that you might wish for.

• It is important to talk about the philosophy of care, a person’s values and beliefs, because those things should guide what specific medical treatments are used, not the other way around.

• Before we talk about the main options, there are two things to consider that often influence people’s wishes for their medical care:
  · Many people feel that the QUALITY of their remaining time is MORE IMPORTANT to them than the amount of time itself. So, in thinking about these choices, it is important to think about what is most important to you.
  · After a new medical problem happens, people who survive can end up worse off than they were before. While we are never able to know for sure what the future holds, we do know that this fact is important to most peoples’ wishes about their care.

Notes for the Team Member
– PAUSE. Answer any questions.

Script Continued

• There are 3 main approaches to medical care in long-term care homes that I will explain.

• It is helpful to understand which one fits best with your values and beliefs.

• The first we call “TRY EVERYTHING TO HELP ME LIVE LONGER.” Here we would use all available medical treatments to try and cure you from whatever you have.

• These may include simple things like using antibiotics for an infection, all the way up to aggressive treatments like trying to get the heart restarted if it stops, and using artificial life support or surgery if needed. This would include transferring you to a hospital for treatments that can only be done there.
Here are some things to know about the “Try Everything to Help Me Live Longer” approach:

- It is what people usually choose when they are active, have a good quality of life, and are looking forward to the future.
- Even then, we are not always successful at extending their life.
- Many medical problems can’t be cured, and, for many, life won’t be prolonged for much longer.
- Frail people, who have lots of medical problems, or have advanced diseases, are less likely to benefit from this approach to medical care, and more likely to suffer complications.
- BUT, even when we cannot cure a medical problem, or extend life, for many medical problems we have treatments that reduce symptoms and may improve or maintain the quality of life.

Notes for the Team Member

- Use “check back” (having the resident/SDM explain in their own words) to assess their understanding of the “Try Everything to Help Me Live Longer” approach. Answer any questions.

Script continued

- The second choice is called “COMFORT CARE.”
- The ONLY goal of comfort care is to ensure that you are comfortable, for whatever time you have left – which may be a long while, a short while, or anything in between. We do not rush death, but we don’t try to artificially delay it either. We accept it, whenever it happens.
- This philosophy means that if a major medical emergency happens, such as your heart or breathing stops, that we do not try to fix that, we accept that death will almost certainly occur. BUT we will ensure that you are comfortable.
- COMFORT CARE IS CARE – it includes any medical, physical, emotional, social and spiritual support needed to ensure you are comfortable.
- Even when we can’t cure or fix a medical problem, we are very good at making sure that the person is comfortable. And although we can almost always do that right here in the long-term care home, if ensuring your comfort requires you going to an emergency room or hospital, we will do that.
- This choice is also called ALLOWING A NATURAL DEATH. It is not euthanasia, or assisting the person in dying. But we do not delay the process of dying with artificial means once it starts. For example, for a person with pneumonia who has not been able to communicate with others and is always in bed, an example of a comfort care approach might be to NOT use antibiotics. We accept that death happens, but we are not helping it along.
- Do you have any questions or thoughts on this “Comfort Care” choice?
• Lastly, you may feel that neither “Try Everything to Help Me Live Longer” or “Comfort Care” are quite right. The third option is in between those two. We call it “THE MENU OF POSSIBLE TREATMENTS.”

• The idea is that there are some types of medical care that you might wish to accept, and others that you might NOT wish to accept.

• For example, you might wish to accept treatments that can be given in the long-term care home, but not want to go to the emergency room or hospital for treatments that cannot be given here.

• Or you might wish to accept treatments here AND agree to go to the emergency room or hospital for certain treatments we cannot give here at the long-term care home.

• Your preference may depend on the situation you are dealing with at the time. For example, some people wish to accept treatments that are relatively simple and allow them to recover quickly and as fully as possible. An example might be receiving intravenous antibiotics to treat pneumonia. However, they may wish not to accept more complicated treatments with unclear outcomes, where they may not recover as well as they would like. Examples of this might be undergoing surgery, getting chemotherapy, or receiving artificial life support.
Script Continued

• If you aren’t sure, it is NOT necessary for you to tell us right now which of the three choices would be your wish. It is OK to think it over and let us know later.

• But it will be helpful to keep these three options in mind and which one fits best with your beliefs and wishes.

• **IF you DO know which of these feels right, feel free to tell us now.**

• Please remember that no matter which of these three approaches seems best now, if a medical emergency happens, we will discuss specific treatment options again at that time. Having this conversation now allows us to better understand your views, wishes and preferences, so it will be easier when an emergency happens, and a decision is needed.

**Notes for the Team Member**

– If they express a clear preference among the 3 main philosophical options, keep it in mind as this will be helpful for the next part of the discussion (Script 8E).

– Answer any further questions as needed. Move onto Script 8E.

**SCRIPT 8E. Address the range of medical options specific for the resident**

**Notes for the Team Member**

– This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.

– Because each resident’s medical issues are different, you will notice that there are no specific suggestions for the words to use.

– While the focus here is understanding the resident’s wishes for specific kinds of treatments for specific kinds of medical problems, your job is to help them understand the full range of possible consequences of those choices, including what is REALISTICALLY ACHIEVABLE, in the context of their actual medical situation, as was discussed in Script 8C.

  - For example, if a person with severe COPD indicates a wish to be intubated and undergo invasive mechanical ventilation, they are not fully informed unless you explain the chance of dying anyway, and even more importantly, that if they survive, breathing problems and disability will not be better than before, and may be worse.

  – However, at the same time it is NOT our place to persuade or convince the resident or SDM to any specific set of care wishes. **Our GOAL is to ensure that the resident receives the kind of care they desire, within the realm of what is achievable.**

  – If the resident indicated they prefer COMFORT CARE, then most of this part of the discussion is fairly simple.
Now we will talk about the medical emergencies and possible treatments that are most likely to happen, based on your medical situation.

**Notes for the Team Member**

- Describe in simple language the MOST LIKELY, SEVERE medical situation(s) that might arise **for this specific resident**. Explain to the resident and others why they are likely.

- Then **AS SIMPLY AS POSSIBLE** describe the possible treatments for the situation(s), and the possible outcomes of the treatments—refer to Table A of this workbook, with additional information for specific clinical situations available in Sections 9 and 10.

- If the resident/SDM indicated that the wished-for approach to care is COMFORT CARE, then the options center around ensuring comfort.

- **If the resident does NOT prefer Comfort Care, then it is important to talk about:**
  1. treatments that can be provided in the long-term care home, versus
  2. treatments which can only be provided by being transferred to the emergency room or hospital.

- Restate and confirm the wishes expressed to make sure everyone is on the same page. DOCUMENT THEM.

- Do the same as above for the **SECOND MOST LIKELY & SEVERE** medical situation to arise for the resident. Restate the wishes expressed to make sure everyone is on the same page. DOCUMENT THEM.

- Do the same as above for any other medical situations that have been identified (in the pre-discussion huddle, and in discussions with the resident’s LTC physician) as being appropriate to discuss here. Restate the wishes expressed to make sure everyone is on the same page. DOCUMENT THEM.

- **Here is a script example:** “We’ve already talked about your weak heart. Sometimes, people with weak hearts fall and break their hips. If this happens, one choice is to keep you in the home and give you pain medicines only. You might survive but won’t be able to walk. Another option is to go to the hospital and repair the bone with surgery. That could help with pain, and you may or may not be able to walk again. But your heart might have trouble handling the surgery and you could have more breathing problems, or you could even die from the stress of the surgery on your body.”
Notes for the Team Member

Regardless of which specific medical issues you discussed for this resident, ALL residents should have the opportunity to clearly express wishes regarding the following 6 items:

1. Antibiotics for infection
2. Artificial feeding tube IF this is allowed and offered in your facility
3. Transfers to the emergency room
4. Hospitalization
5. Resuscitation/CPR

**NOTE:** if the resident indicated that they would NOT want to be transferred to the emergency room (item #3) or hospitalization (item #4), then **this item should automatically be “No.”**

6. Insertion of a breathing tube and use of a breathing machine
(a form of artificial life support)

**NOTE:** if the resident indicated that they would NOT want to be transferred to the emergency room (item #3) or hospital (item #4), then **this item should automatically be “No.”**

**Note:** One possible way to record these wishes is to use these four categories:

- Never
- Yes, but with conditions, and identify the conditions in which it would/wouldn’t be acceptable
- Yes, with no conditions (i.e., do it, regardless of the situation)
- Undecided

- Restate your understanding to make sure everyone is on the same page. DOCUMENT EVERYTHING.
- Answer any further questions as needed. Move onto Script 8F.
SCRIPT 8F: Conclude the discussion

Notes for the Team Member
- This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.
- The LTC team can now call the meeting to a close.
- Ask if there are any final questions and answer them.
- **Ensure that the discussion is documented, including your evaluation of the resident’s capacity, and wishes/preferences about medical care and treatments.**

Script
- Today’s meeting was good and we all now have a better understanding of your wishes for medical care as of now.
- Remember, it is OK for you to change your mind. If and when an emergency happens, the treatment choices will be discussed, but knowing your wishes at this point will help us to have these conversations in the future.
- If your medical conditions change, your wishes may change too, and we will want to go over these things again.
- Thank you all for coming today.

Notes for the Team Member
- Document (be specific) whether, in your judgement, the resident demonstrated:
  Full, partial or lacked capacity to understand/express their wishes regarding medical care
Additional Scripts for Specific Clinical Situations

What follows are scripts for particular clinical situations. They are written for talking to a resident about their wishes regarding medical management when they are at risk of experiencing the specific clinical situation outlined. However, with a little adjustment of the words, you can use these scripts to discuss options after the situation has already occurred. These scripts can be used by themselves, or if appropriate, as part of the full BABEL ACP discussion. If present, a physician or nurse practitioner should lead these script-based discussions.

9A. Antibiotics for pneumonia in residents with advanced neurologic disorders

Preliminary Information

1. Neurologic disorders and pneumonia are common in LTC residents.
   a. Pneumonia is an infection of the lungs.
   b. Pneumonia is common in this stage of life and is often the final illness and immediate cause of death in LTC residents.
   c. The most common neurologic disorders in LTC residents are: dementia, stroke, and Parkinson’s Disease.
   d. Other neurologic disorders include: Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis (MS), Muscular Dystrophy, Huntington’s Disease, and others.

2. Symptoms of pneumonia in elderly people are highly variable. It can cause difficulty breathing (shortness of breath), cough, fever, fatigue, confusion, loss of appetite, delirium, coma, and other symptoms.

3. But other common conditions can also cause shortness of breath in the elderly — including heart failure, blood clots to the lungs (pulmonary embolism), and lung disease from cigarette smoking.

4. There is an important relationship between neurologic disorders and pneumonia. ASPIRATION is when saliva or food go down the windpipe into the lungs. Many neurological conditions – including those listed above – can progress to the point that residents cannot “control their airway,” and as a result they aspirate, which can lead to pneumonia.

5. It is difficult to identify when a resident has reached the end stage of a neurological condition. One research study found that 75% of all deaths in persons with neurologic diseases were identified by the presence of one or more of the following four conditions:
   e. Aspiration
   f. Cognitive impairment plus infection
   g. Rapid physical decline
   h. Significant complex symptoms, including pain

6. If a resident with a neurologic disorder develops any of the four symptoms listed in point 5 above, it is recommended to discuss the resident’s wishes with respect to antibiotics, even if pneumonia has not yet occurred.

7. Antibiotics can help the body fight the infection that is pneumonia. However, in people whose advanced neurologic diseases cause them to aspirate, they will continue to aspirate and usually get pneumonia repeatedly. Therefore, the antibiotics for pneumonia in someone with a serious and progressing neurological condition may or may not delay death.
Notes for the Team Member
– This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.

Script
• We want to discuss the fact that because you have [NAME OF THE NEUROLOGICAL DISORDER], there is a high risk of getting pneumonia.

• That disease can make it so that swallowing doesn’t work right, and germs from the mouth and throat can go down “the wrong way,” get into the lungs, and cause infection. The infection is pneumonia and it can cause shortness of breath and make it hard to get enough oxygen to the body.

Notes for the Team Member
– Pause.

– Allow the resident/SDM to ask any questions that they may have.

Script continued
• We have looked for other reasons why this swallowing problem exists for you, but mainly it is because the [NEUROLOGICAL DISORDER] has gotten worse.

• And I’m very sorry to say we cannot fix that.

• I am also sorry to let you know that you have developed problems indicating a very advanced and final phase of the [NEUROLOGICAL DISORDER].

• What are your thoughts about this?

Notes for the Team Member
– Allow the resident/SDM to ask any questions that they may have. You might provide examples to justify the impression that the neurological disorder has gotten worse (e.g., more choking on food lately).

– If previously documented wishes and preferences exist, you may remind the resident/SDM of these now.

Script continued
• If you get pneumonia, we can give you antibiotics, and they might help control the infection this time around.

• The antibiotics might help you feel better for a while, but because the [NEUROLOGICAL DISORDER] remains so severe, it is likely only a matter of time before you get pneumonia again. We do not know if that will happen soon or a long time from now.
Notes for the Team Member
- PAUSE. Allow the resident/SDM to ask any questions that they may have.

Script
- So, given the situation, we would like to know whether you would wish to get antibiotics if you get pneumonia. This might give you a bit more time, but it cannot fix the [NEUROLOGICAL DISORDER] that is the cause of the problem.
- It’s OK not to take antibiotics for pneumonia and let nature take its course. If that is what you would want, we would do everything to keep you comfortable and treat any shortness of breath or other distress that happens.

Notes for the Team Member
- Ask the resident/SDM(s) to share their thoughts. Use “check back” (having the resident/SDM(s) explain in their own words) to assess their understanding of their clinical state and the benefits/repercussions of taking antibiotics. Provide more information and discuss as needed.
- Allow the resident/SDM(s) to ask any questions that they may have.
- Be sensitive that their ideas and wishes may have evolved since previous discussions, and that they may be experiencing anxiety in relation to the failing health and potential associated discomfort.

Script Continued
- I realize this is a lot of information to take in.
- We are always available to answer any questions or concerns you may have. Do you have any questions at this time?

Notes for the Team Member
- Answer questions as needed.

Script Continued
- So, if I understand correctly, if you were to get pneumonia, your wish at this time would be that we [RESTATE YOUR UNDERSTANDING OF THE RESIDENT’S WISHES ABOUT ANTIBIOTICS FOR PNEUMONIA].

Notes for the Team Member
- Document this discussion, being as specific as possible.

REFERENCES
9B. Care of advancing heart failure

Preliminary information

1. Heart failure affects up to 1 out of every 5 LTC residents. Many will be hospitalized, and about half will die within one year. Many LTC residents with heart failure die shortly after moving to the LTC home. Residents with heart failure who are frail have an even higher risk of death.

2. There are three ways that residents in LTC die of heart failure: sudden cardiac death, progressive heart failure, and death related to a different medical condition.
   a. Sudden cardiac death is rapid and painless. However, some residents with heart failure have a defibrillator implanted in their chest. A defibrillator provides an electric shock to the heart when it starts beating irregularly or stops beating. The electric shock is uncomfortable and can lead to anxiety and fear. In a sense, the defibrillator may “rob” the patient of the option of sudden, and otherwise painless death.
   b. Death from progressive heart failure: This involves severe swelling, particularly of the legs and belly, which can be uncomfortable. There can also be fluid buildup in the lungs, which leads to serious shortness of breath, anxiety, fear, and discomfort.
   c. Death from a different medical condition: People with heart failure are more likely to experience other conditions. Often these include smoker’s lung disease (COPD, emphysema), pneumonia, strokes, or falls and fractures.

3. LTC homes can provide palliative/comfort care for residents with severe heart failure. This type of care includes understanding the resident’s wishes and developing a treatment plan consistent with the resident’s wishes—for example, appropriate use of diuretics (water pills), drugs for the heart, and medication to reduce shortness of breath or pain.

4. For residents with an active implanted defibrillator, particularly those who do not wish to get CPR, it is important to talk about turning off the device. These residents are usually followed in a specialty cardiology clinic, so it may be important to have providers from that clinic involved in this discussion. The defibrillator can be easily turned off. It is important for the resident/SDM to understand that:
   d. Deactivating the defibrillator does not involve surgery or complex intervention.
   e. Deactivating the defibrillator will not hurt at all: the device remains in place.
   f. Deactivating the defibrillator does not mean the resident will die shortly thereafter. The resident may live for a long time and may never experience a cardiac arrest.
   g. The goal of deactivating the defibrillator is to allow a natural death to occur when the heartbeat stops, painlessly and quickly.

For more on implanted defibrillator deactivation see: (https://www.corhealthontario.ca/resources-for-healthcare-planners-&-providers/icd/ICD-Deactivation-Document-FINAL-April-20-2017.pdf). You can also consider developing, with your local arrhythmia clinic, a protocol to facilitate the deactivation of implanted defibrillators for residents who chose to do so.
Script

- I would like to talk about your heart. The records mention that you have a condition called heart failure, which causes swelling, and can cause fluid in the lungs that makes it hard to breathe.

- How much do you know about your heart condition?

Script Continued

- Heart failure is a complicated problem. There are medications for it, but it is NOT curable, and it almost always worsens over time.

- In many cases, we can give medications to help improve the symptoms of heart failure and keep you here in the long-term care home, without the need to be sent to the emergency room or hospital.

- BUT, there may come a time when the heart failure gets so bad that an important choice will need to be made.

- That choice is to go to the hospital and get more aggressive care like intravenous medications, and machines to **temporarily** help with breathing or to stay here at the long-term care home, where we will keep you comfortable, but you may die sooner.

- How do you feel about these choices?
Notes for the Team Member

- PAUSE. Ask the resident/SDM(s) to share their thoughts. Use “check back” (having the resident/SDM(s) explain in their own words) to assess their understanding of their clinical state and the options presented. Answer all questions they may have.

- It may be appropriate to again discuss the three available philosophies of care (the “big picture”) as outlined in Script 8D.

- Talk about the possibility of going to the emergency room or hospital to get SOME kinds of care (such as intravenous medications), but to “draw the line” at artificial life support such as artificial mechanical ventilation.

- It may be appropriate to talk about palliative care provided in the LTC home.

- If appropriate, address turning off the defibrillator if the resident has one.

- Be sensitive that their ideas and wishes may have evolved over time, and that they may be experiencing anxiety in relation to their failing health and potential associated discomfort.

Script Continued

- If I understand correctly, if your heart failure were to get worse, your wish at this time would be that we [RESTATE UNDERSTANDING OF THE RESIDENT’S WISHES ABOUT GOING TO THE EMERGENCY ROOM OR HOSPITAL FOR MORE AGGRESSIVE TREATMENT FOR HEART FAILURE].

Notes for the Team Member

- Document this discussion, being as specific as possible.

9C. Use of artificial feeding tubes

Preliminary information

1. Meals are more than just a way of addressing needs of the body. Meals and mealtimes also have personal, social, cultural, and religious meaning for many people.

2. People who are very frail, or who have neurologic diseases, can develop swallowing problems, making it hard to eat and drink. This also puts the person at high risk of choking, or aspirating food or liquids (including saliva), potentially causing pneumonia and other breathing problems.

3. For frail LTC residents, losing the ability to safely swallow food or liquids often indicates that the final part of life has arrived.
4. When this happens, it is difficult to keep the resident well nourished. The usual first things that are done in this situation include having a family member or LTC team member carefully hand feed the resident, and altering the consistency of food to make it easier and safer to swallow. But when those fail, there are three choices left:

a. Inserting a nasogastric feeding tube, through the nose into the stomach, and putting liquid food directly into the stomach. This is only a temporary measure and some LTC homes do not use this approach.

b. Having surgery to install a feeding tube through the wall of the abdomen either into the stomach (PEG) or small intestine (PEJ) and putting liquid food directly into the stomach or intestine.

c. Allowing the resident to eat in the usual way what they can and want to, and accept that aspiration and breathing problems will eventually happen. This option is sometimes called “pleasure eating.”

5. In these situations, for LTC residents, difficulties with intake of nutrition are a natural consequence of the diseases they have. It is important to recognize that while such people lose weight, they usually do NOT complain or appear to suffer from hunger.

6. Research indicates that in severe dementia, feeding by a feeding tube does NOT lead to a longer life, more comfort, better quality of life, function, or reduced risk for pneumonia.

7. What is certain is that whether nutrition is provided, the underlying condition that is the cause of the swallowing problem continues to worsen.

---

**SCRIPT 9C**

**Notes for the Team Member**

– This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.

**Script**

- We have noticed that you are having trouble swallowing food and liquids safely, without choking.
- Have you noticed this as well? What are your thoughts on this?

**Notes for the Team Member**

– Allow the resident/SDM(s) to ask any questions that they may have.
Script *Continued*

- We have looked for other reasons for this difficulty with eating and swallowing, but mainly it exists because the medical condition(s) responsible have gotten a lot worse. We’re sorry to say that we cannot fix that.

- We are also very sorry to say that this tells us that you have reached a final phase of life.

**Notes for the Team Member**

- Allow the resident/SDM(s) to ask any questions that they may have. You might provide examples to justify the impression that the neurological disorder has gotten worse (e.g., more choking on food or liquids).

Script *Continued*

- We will of course continue to help you. There are a couple of things we could do.

- The first option is what is sometimes called pleasure eating. We help you to eat in the usual way, understanding and accepting that you will have swallowing problems, and will be at high risk for coughing and choking, and for related problems that often shorten life.

- The second option: Some people ask about feeding tubes. There are two types of feeding tubes.

- The first type of feeding tube involves placing a tube through the nose and into the stomach, through which liquid food is given a few times a day. The tube can be uncomfortable.

- The other type of feeding tube requires a surgery where a hole is made in the wall of the belly, and a tube is inserted directly into the stomach. This tube stays in place and a bag of liquid food is given through the tube.

**Notes for the Team Member**

- Allow the resident/SDM(s) to ask any questions that they may have.
• Although it may sound strange at first, it is VERY IMPORTANT for you to know that in this situation, use of a feeding tube often does NOT help people live longer, or reduce the chance of getting material going down “the wrong way” into the lungs and causing problems. Also, some people with feeding tubes get very upset by them and try to pull them out.

• The reason that artificial feedings through tubes do not help people in this situation to live longer is probably related to the risks and complications of the tubes and the artificial feedings (e.g., the possibility of bleeding or infection or pain near the insertion site). Also, as I said before, when these swallowing problems show up, we know that this means that the final part of life has arrived.

• Another very important thing we know is that when this part of life arrives, even though people lose weight, it is rare for them to complain or appear to suffer from hunger.

• The problems with taking food and swallowing are due to the advancement of your illness.

• What we know for certain is that a feeding tube will not improve the underlying illness that is causing this swallowing problem and can make the last months of life more uncomfortable.

Notes for the Team Member

– PAUSE. Ask the resident/SDM(s) to share their thoughts. Use “check back” (having the resident/SDM(s) explain in their own words) to assess their understanding of their clinical state and the options presented. Answer all questions they may have.

– Be sensitive that the resident’s ideas and wishes may have evolved since prior discussions, and that they may be anxious about their failing health and potential associated discomfort.

Script Continued

• I realize this is a lot of information to take in. Do you have any questions at this time?

• Can you share some of your thoughts about whether or not you would want a feeding tube?

Notes for the Team Member

– Address anything that the resident/SDM is unclear about.

– Ask the resident/SDM to talk about their thought processes. Provide more information and discuss as needed. If the resident appears to hesitate or not fully understand, make sure that the SDM does, using a similar approach.

– Answer questions as needed.
Script  Continued

- So, if I understand correctly, your current wish would be that we [USE/NOT USE] a feeding tube.

Notes for the Team Member

- Document this discussion, being as specific as possible.

REFERENCES


9D.  Permanent/long-term use of artificial hydration (intravenous or subcutaneous fluids)

Preliminary information

1. Taking in fluids, to keep hydrated, is necessary for life. For LTC residents, there are temporary and permanent reasons why they may be unable to drink enough fluids.
   a. Temporary Reasons: These are usually acute problems that temporarily cause excessive vomiting or diarrhea, or make it hard to drink liquids.
   b. Permanent Reasons: This primarily happens when chronic disorders become so severe that the person has swallowing problems, or they are no longer interested in drinking. The script below is about Permanent Reasons for dehydration only.

2. Swallowing problems make the person at high risk of choking or aspirating food, liquids, or saliva, potentially causing pneumonia and other breathing problems.
   c. This is common in LTC residents, and happens often with advanced dementia, frailty, Parkinson’s disease, other neurologic disorders, or any advanced disease.
   d. For residents who are unable to maintain adequate hydration and nutrition on their own, you should consult with your home’s dietitian about best practices of modified food and fluid textures. While such approaches can provide some management of this problem, in the long term such individuals often do eventually fail to maintain adequate hydration and nutrition.

3. Losing interest in drinking (and eating) commonly occurs towards the end of life with advanced dementia, frailty, and other diseases.
   e. While this leads to residents becoming dehydrated, they do not usually suffer from thirst.
   f. Research has shown that with advanced dementia, fluids/food given artificially do NOT reduce risk for pneumonia, improve quality of life, improve function or comfort, or prolong survival.
   g. Whether or not artificial fluids are provided, the underlying condition that is the cause of the swallowing problem or lack of interest in drinking continues to worsen.
   h. An important thing to recognize is that these situations usually indicate that the final stages of life have begun.
4. There are three main choices when hydration problems are caused by permanent/long-term reasons:

i. The resident remains in the LTC home and is encouraged to take in fluids by mouth.

j. The resident remains in the LTC home and receives artificial fluids through a needle inserted just below the skin into the subcutaneous tissue, known as the hypodermoclysis. Only some LTC homes are set up to do this.

k. The resident is admitted to the hospital and receives fluids intravenously. Some LTC homes have this capability within the home.

5. As shown in script 9D, for permanent/long-term reasons behind hydration problems, the focus of discussion is that even after aggressive rehydration, the problem will recur. In other words, we cannot fix the cause, and there is no good long-term solution.

SCRIPT 9D

Notes for the Team Member
– This script is directed at the resident. If the resident is completely unable to participate in the discussion, the wording will need to be altered slightly so that questions are directed at the SDM.

Script
• We would like to talk to you about a problem we have noticed. It seems that you have trouble drinking enough liquids to stay well hydrated. Have you noticed this as well?

Notes for the Team Member
– Allow the resident/SDM to share thoughts and ask any questions that they may have.

Script Continued
• We believe that the reason behind not being able to drink enough fluids is [explain the permanent/long-term cause in this case].

• This is usually permanent, and I am sorry to say this, but this usually indicates that the final stages of life have begun.

• [IF RESIDENT IS ON THICKENED FLUIDS]: As you know we have tried thickened fluids, but you are still not getting enough fluids.

• It is also important to note that people do not usually feel thirsty, even though they do not drink enough fluids. I realize this is difficult information to take in. Before going on to talk about the options that are available, do you have any questions?

Notes for the Team Member
– Try to ensure the resident and/or SDM understands the gravity of this situation. ONLY discuss the option of giving fluids through a subcutaneous needle if that is something that your LTC home is set up to do.
**Script Continued**

- Now let’s talk about what options are available to deal with this problem.

- **(CHOICE 1):** One option is to give fluids artificially through a needle into a vein or under the skin.

- Getting fluids into a vein—intravenously—usually requires going to the hospital. You will be given fluids through the vein, but this will stop when you return to the long-term care home.

- **(CHOICE 2):** The other option is to help you take fluids by mouth and stay here in the long-term care home. If this leads to being thirsty, then we will provide Comfort Care as we have talked about before, to make sure that you are comfortable and taken care of in the home.

- Do you have any questions at this time?

**Notes for the Team Member**

- Make sure that the resident and/or SDM(s) understand how, in this situation, giving artificial fluids through a needle should not be done permanently. Ask if they understand all of this. If “No,” then explain it again. If “Yes,” then ask them to describe it to you in their own words.

- After answering any questions and providing any clarifications needed, ask which of the two main choices is preferred. Document this discussion, being as specific as possible.

- **IF the desired choice is CHOICE 1: artificial fluids through a needle (either IV or subcutaneously), then do this part of the script:**

**Script Continue**

- If I understand correctly, your current wish would be to receive artificial fluids through a needle, even if that means going to the hospital.

- I need to tell you that this approach has limitations as it does not fix the cause of the problem. Not being able to drink enough fluids is going to recur. There are risks of doing this, and it is not possible or practical to continue giving fluids through a needle indefinitely.

- So, we need to discuss how many times and how long to give this a try.

- One option is to try it once or maybe twice, and for a limited time but if it recurs to then switch over to an approach where providing comfort at the end of life is our goal.

**Notes for the Team Member**

- Try to negotiate something reasonable that the resident/SDM can accept.

- Document this discussion, being as specific as possible.
Info to Support ACP Discussions in Other Clinical Situations

This section contains information for you about other situations that should prove useful in informing ACP discussions with LTC residents and their SDMs.

10A. Chronic Obstructive Pulmonary Disease (COPD)

1. In Canadian LTC homes, 8–20% of residents have COPD and it is a common cause of death.

2. COPD is marked by “exacerbations”—intermittent worsening of breathing. These can be caused by viral or bacterial infections of the airways or the lungs. COPD exacerbations sometimes require care in a hospital and may include use of artificial life support in the form of insertion of a breathing tube (intubation) attached to a breathing machine (ventilator).

3. Like heart failure, COPD in LTC residents is often complicated by the presence of other disorders, and by geriatric syndromes such as frailty. And like heart failure, predicting the amount of life remaining for LTC residents with COPD can be challenging.

4. A large study of 73,000 patients hospitalized with a COPD exacerbation in Quebec, who were followed for up to 17 years, demonstrated the following:
   a. The best predictor of future hospitalizations/death is the number of prior hospitalizations.
   b. Health/function deteriorates faster after a second hospitalization for COPD exacerbation.
   c. Mortality rate rises after each COPD exacerbation.

5. According to management guidelines from the American Medical Directors Association, the following things are clues that an LTC resident with COPD may have less than 6 months to live:
   a. Shortness of breath at rest.
   b. Losing more than 10% of body weight in the prior 6 months.
   c. More frequent emergency room visits or hospitalizations.

6. It is important to discuss options for residents with severe COPD. The main options are:
   a. Aggressive care, even including transfer to hospital and artificial life support (hopefully which will be only temporary).
   b. Transfer to hospital but without use of artificial life support.
   c. More conservative care, provided in the LTC home only such as oxygen or medications.
   d. Comfort care (i.e., palliative care).

REFERENCES

COPD Management in the Post-Acute and Long-Term Care Setting 2017. Columbia, MD, The Society for Post-Acute and Long-Term Care Medicine.
1. Patients over the age of 75 years are the fastest growing age group with end-stage renal disease.

2. Among LTC residents who are on dialysis, about half die within 6 months, and even more die within 12 months.

3. Residents who start dialysis within 3 months of LTC admission have even higher rates of death. And 80–90% of these individuals experience declines in functioning and thinking after dialysis starts.

4. Other factors indicating higher mortality for LTC residents with kidney failure are: problems with physical functioning, problems with thinking, coronary artery disease, and decubitus skin ulcers.

5. Although dialysis DOES extend the time alive for LTC residents with kidney failure, an important issue for these individuals is the quality of life.

6. It is OK to stop doing dialysis, and the rate at which people are choosing this option has increased in recent years. Death after stopping dialysis is almost always very peaceful and occurs within days to a few weeks.

7. It has been recommended that discussions occur with LTC residents who are already on dialysis. Residents should be given the chance to consider the likelihood of survival and quality of life, and whether they want to go on – or stay on – dialysis. It is also appropriate to repeat this discussion periodically, because at some point they may change their minds – and we won’t know that unless we ask.

8. For LTC residents who have worsening kidney function and seem to be approaching the point of needing dialysis, it is important to have discussions about the options of going on dialysis versus NOT going on it. This discussion should be in the context of talking about the quality of remaining life, and the negative effects of dialysis on physical and mental function.

REFERENCES

1. Diabetes mellitus affects 20–30% of LTC residents across Canada.

2. Current evidence and treatment guidelines suggest that for frail, elderly people with diabetes, less strict control of blood sugar is appropriate, and may be safer than “tighter” control.

3. LTC clinicians should therefore expect that residents who are frail (and their SDMs), who have been used to hearing the message that tight glucose control is essential, may require education and support to understand if a major shift in treatment goals should be an option.

4. The 2018 Canadian Diabetes guidelines offer the guidance below:

**Guideline recommendations for key clinical outcomes for older people with diabetes from Diabetes Canada (DC), American Diabetes Association (ADA) and International Diabetes Federation (IDF)**

<table>
<thead>
<tr>
<th>MEASURE</th>
<th>ADA</th>
<th>DC</th>
<th>IDF</th>
</tr>
</thead>
<tbody>
<tr>
<td>A1C</td>
<td>HEALTHY&lt;br&gt;&lt;7.5%</td>
<td>FUNCTIONALITY INDEPENDENT&lt;br&gt;&lt;7.5%</td>
<td>FUNCTIONALITY INDEPENDENT&lt;br&gt;&lt;7.5%</td>
</tr>
<tr>
<td></td>
<td>COMPLEX / INTERMEDIATE&lt;br&gt;&lt;8.0%</td>
<td>FUNCTIONALITY DEPENDENT&lt;br&gt;7.1 – 8.0%</td>
<td>FUNCTIONALITY DEPENDENT&lt;br&gt;7.0 – 8.0%</td>
</tr>
<tr>
<td></td>
<td>VERY COMPLEX / POOR HEALTH&lt;br&gt;&lt;8.5%</td>
<td>FRAIL AND/OR DEMENTIA&lt;br&gt;7.1 – 8.5%</td>
<td>SUB-LEVEL FRAIL&lt;br&gt;&lt;8.5%</td>
</tr>
<tr>
<td>END OF LIFE</td>
<td></td>
<td>A1C measurement NOT recommended. Avoide symptomatic hyperglycemia and any hypoglycemia.</td>
<td>Avoide symptomatic hyperglycemia</td>
</tr>
<tr>
<td>BLOOD PRESSURE</td>
<td>HEALTHY&lt;br&gt;&lt;140/80 mmHg</td>
<td>FUNCTIONALITY INDEPENDENT WITH LIFE EXPECTANCY &gt;10 YEARS:&lt;br&gt;&lt;130/80 mmHg</td>
<td>FUNCTIONALITY INDEPENDENT&lt;br&gt;&lt;140/90mmHg</td>
</tr>
<tr>
<td></td>
<td>COMPLEX/INTERMEDIATE&lt;br&gt;&lt;140/80 mmHg</td>
<td>FUNCTIONALITY DEPENDENT, ORTHOSTASIS OR LIMITED LIFE EXPECTANCY:&lt;br&gt;Individualize BP targets</td>
<td>FUNCTIONALITY DEPENDENT&lt;br&gt;&lt;140/90mmHg</td>
</tr>
<tr>
<td></td>
<td>VERY COMPLEX/POOR HEALTH&lt;br&gt;&lt;150/90 mmHg</td>
<td></td>
<td>SUB-LEVEL FRAIL&lt;br&gt;&lt;150/90mmHg</td>
</tr>
<tr>
<td>END OF LIFE</td>
<td></td>
<td></td>
<td>Strict BP control may not be necessary</td>
</tr>
<tr>
<td>LDL-C</td>
<td>&lt;1.8 mmol/L</td>
<td>&lt;2.0 mmol/L or &gt; 50% reduction from baseline</td>
<td>&lt;2.0 mmol/L and adjusted based on CV risk</td>
</tr>
</tbody>
</table>

Adapted from ADA (42) and IDF (40).
A1C, glycated hemoglobin; BP; blood pressure; CV, cardiovascular; LDL-C, low density lipoprotein cholesterol.
10D. Stopping medications (deprescribing)

1. Older LTC residents take a lot of medications. In 2014, over 60% of Canadian LTC residents were on at least 10 different medications.

2. Many of these residents are nearing the end of their lives, and for many of them, we know that relief of symptoms affecting quality of life are more important than duration of life.

3. Physicians make decisions about prescribing medications by balancing the potential benefits with the potential side effects and other harms.

4. It is important to recognize that frail, elderly people are more likely than non-frail and younger people to experience side effects and harms from medications. These can include: confusion, dulled thinking, constant sleepiness, excessively low (or high) blood pressure, constipation, diarrhea, trouble with urination, and many other things.

5. For older, frail, LTC residents who are towards the end of life, medications prescribed to prevent future events, such as heart attacks and strokes, are likely to be ineffective in preventing such medical events, or death.

6. In recent years, medical experts have identified groups of prescription medicines which carry greater potential risk than potential benefit. These are contained on what is called the modified Beer’s List of drugs that should be avoided in the elderly.

   - A good example is statins, used for high cholesterol. The benefit of these drugs for avoiding heart attacks and lengthening life are over the LONG TERM. Thus, in elderly LTC residents with end-stage diseases and a limited life expectancy, the chance of benefit from continuing statins is little to none.

   - In a study in older adults with an average age of 75 years, many of whom had cancer or dementia, stopping the statin had no effect on mortality and those who did NOT continue the statins had a BETTER quality of life.

7. The Canadian Deprescribing Network (https://www.deprescribingnetwork.ca/algorithms) offers useful guides for withdrawal of certain classes of medications in older adults, especially:

   - Proton Pump Inhibitors
   - Diabetes drugs
   - Antipsychotic drugs
   - Benzodiazepines
   - Acetylcholinesterase inhibitors and memantine
Clinical Outcome Diagrams

This section contains survival illustrations that can be used during ACP discussions with the resident and SDM/family. They indicate average survival rates for groups of people in LTC homes. For any single person we never know what the future holds with absolute certainty, but it may help individuals to know what they can expect, on average.

<table>
<thead>
<tr>
<th>11A. Survival After Cardiac Arrest</th>
<th>11B. Survival with Severe Frailty</th>
<th>11C. Survival for CHESS Score 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>START (100 ALIVE)</td>
<td>1 MONTH LATER (3 ALIVE)</td>
<td>START (100 ALIVE)</td>
</tr>
<tr>
<td><img src="image1" alt="Diagram" /></td>
<td><img src="image2" alt="Diagram" /></td>
<td><img src="image3" alt="Diagram" /></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>11D. Survival for CHESS Score 4</th>
<th>11E. Survival for CHESS Score 5</th>
<th>11F. Congestive Heart Failure (CHF)</th>
</tr>
</thead>
<tbody>
<tr>
<td>START (100 ALIVE)</td>
<td>6 MONTHS LATER (28 ALIVE)</td>
<td>START (100 ALIVE)</td>
</tr>
<tr>
<td><img src="image5" alt="Diagram" /></td>
<td><img src="image6" alt="Diagram" /></td>
<td><img src="image7" alt="Diagram" /></td>
</tr>
</tbody>
</table>
SECTION 12

The BABEL ACP Pre-Discussion Guide for Long-Term Care Team Members

This pre-discussion guide provides background information on the BABEL Approach to Advance Care Planning (BABEL ACP) including why ACP is so important in long-term care (LTC), as well as who – and what – should be included in ACP discussions. It should be reviewed by LTC team members before supporting BABEL ACP discussions with residents.

What is BABEL ACP?
The BABEL Approach to Advance Care Planning (BABEL ACP) provides communication tools to long-term care (LTC) team members to support advance care planning (ACP) conversations with a focus on each resident’s needs and wishes. BABEL ACP can be used as a stand alone approach to ACP or to complement other approaches by helping LTC team members better tailor conversations around the health outcomes most likely to be experienced by a resident. BABEL ACP is informed by research, best practices and extensive experience in ACP.

What is advance care planning and why is it important?
The foundation of ‘good care’ is getting to know each resident as an individual: their values, beliefs, fears and wishes. Unfortunately, these discussions may be avoided out of not knowing what to say or being unsure about how to respond. However, giving our residents the opportunity to talk about what they want, and what they fear, helps them gain a sense of control, and provides reassurance that we will do our best to meet their needs.

Advance care planning (ACP) is a set of processes to help people think about, talk about, and document their wishes for healthcare in the event they become unable to speak for themselves.

It includes designating substitute decision makers (SDMs) who will represent residents’ interests and wishes if and only if residents cannot speak for themselves.

The need for effective ACP for residents living in LTC is clear. As residents move towards their end-of-life journey, their health and symptoms change. It is the responsibility of LTC team members to make sure that residents’ end-of-life wishes are honoured. Team members should be familiar with, and able to facilitate, ACP with residents, their SDMs and other family members.

IMPORTANT
This section is meant to be a stand-alone guide for LTC team members who are supporting but not leading the preliminary and/or full BABEL ACP discussions. It should be printed and shared with these team members ahead of ACP conversations with residents. Those who are leading the preliminary and full BABEL ACP discussions should review and refer to the full BABEL ACP workbook rather than this guide.
What is a substitute decision maker?

A substitute decision maker is a person or persons who can legally make a medical or personal care decision for a resident, if the resident cannot make the decision for themselves. A substitute decision maker is someone that the resident trusts to speak on their behalf if they are unable to do so. It is vital that the role of substitute decision makers is to let the care team know what the resident would or would not want, not what the substitute decision maker wants.

What is involved in an ACP discussion?

Although most residents have already thought about what constitutes quality of life for them, they often don’t know how their goals and preferences will play out given their particular medical condition. Residents and family members can make better decisions when they are fully informed about the nature and likely course of a resident’s disease, as well as the potential outcomes of the treatment options that are available. ACP discussions are meant to provide this type of detailed information to residents and their SDM(s) and to provide space where residents and SDM(s) can ask questions and share their thoughts, wishes and preferences in regards to treatment options. While treatment options will always be revisited when a medical emergency happens, having ACP discussions can help the LTC team - and the resident’s SDM(s) – to be better prepared to make a decision.

ACP discussions should take place with residents and SDMs when they move into the LTC home, when the resident’s situation changes, and on a yearly basis. Additional ACP discussions can take place anytime.

Why should team members encourage ACP discussions?

Residents should be encouraged to engage in ACP discussions, because they:

1. Respect a resident’s right to self-determination at the end-of-life.
2. Improve resident/family members’ satisfaction with end-of-life care.
3. Decrease the level of distress experienced by family
4. Decrease unwanted medical tests and treatments if this is not the resident’s wish.

Resources

2. Ontario version: https://www.speakupontario.ca/resource/acp-workbook-en/
4. Care Recommendations from the Coalition for Compassionate Care: http://coalitionccc.org/tools-resources/nursing-homes/care-toolkit/

What is BABEL ACP?
The BABEL Approach to Advance Care Planning (BABEL ACP) provides communication tools to long-term care (LTC) team members to support advance care planning (ACP) conversations with a focus on each resident’s needs and wishes. BABEL ACP can be used as a standalone approach to ACP or to complement other approaches by helping LTC team members better tailor conversations around the health outcomes most likely to be experienced by a resident. BABEL ACP is informed by research, best practices and extensive experience in ACP.

What are the objectives of the BABEL ACP discussions?
To help your resident and their substitute decision makers (SDMs):

1. Prepare for medical emergencies
2. Understand the medical situation and prognosis
3. Discuss their philosophy of life and death
4. Understand the realistic and achievable resident goals
5. Clarify the resident’s wishes regarding specific medical management options.

Is there a capacity assessment involved in BABEL ACP?
The assessment of your resident’s capacity to make their own decisions is built into the script-guided discussions of BABEL ACP.

Are there any handouts for residents and LTC team members ahead of the discussion?
We have created and collected excellent written and online materials about ACP. These include: Factsheets for residents, SDMs and team members that inform the key aspects of BABEL ACP The BABEL ACP workbook that provides instructions for LTC team members on how to conduct ACP discussions, including conversational scripts to follow. The workbook includes diagrams that may help residents and SDMs to understand the prognostic implications of certain high-risk characteristics. A pamphlet for residents called Speak Up, created by a consortium of Canadian organizations, that many people have found helps them better understand these complicated issues.
Are the residents involved in ACP discussions at high risk of a medical emergency or death?

All residents in LTC should be involved in ACP discussions, ideally as soon as they move into the LTC home and on a routine basis after that. Residents should be involved in ACP discussions regardless of whether they are at a severe risk of medical emergency or death. The following, all available from the regularly collected MDS² indicate a high risk of dying in the next 6–12 months: (a) a CHESS score ≥3, (b) leaving >25% of food uneaten, (c) congestive heart failure, or (d) cancer.

A reminder about CHESS

CHESS stands for “Changes in Health, End-stage disease and Symptoms and Signs.” Using data routinely and serially collected in long-term care homes in most of Canada (including your province), it culminates in a score that ranges from 0-5. Here is the relationship between CHESS score and survival among long-term care residents in Canada: Reference: Stuart et al. J. Am. Med. Dir. Assoc., 19(2):106-109, 2017
What is the plan of action for this ACP discussion?

**Quick team guddle (prior to meeting with the resident/SDM):**
Summarize prior ACP discussions/decisions and set out plan/goals for this discussion

**Join resident/family**
Introductions all around

**SDM discussion (script-guided)**
- Confirm the identity of the SDM(s)
- Explain SDM responsibilities and roles
- Prepare the SDM for emergencies

**PHYSICIAN OR NP LED (IF PRESENT)**
**Clinical situation (some scripts provided)**
- Discussion of resident’s current medical situation & prognosis
- Implications for survival & ability to respond to treatments
- Explain the different, alternative philosophies of care that exist

**Discussion of medical issues/choices (script-guided)**
Using the resident specific medical context, discuss the full range of possible treatment options, both inside and outside the long-term care home
SECTION 14

Checklist for the Full BABEL ACP Discussion

RESIDENT NAME: ______________________________________________________________________________________

DATE OF THIS DISCUSSION: _____________________________________________________________________________

DATE OF CHECKLIST COMPLETION: _______________________________________________________________________

NAME OF TEAM MEMBER DISCUSSION LEADER: ___________________________________________________________________

CHECK ALL THAT PARTICIPATED (EITHER IN PERSON, PHONE, SKYPE, OR ANY OTHER WAY IN “REAL TIME”):

□ RESIDENT      □ NURSE(S)      □ PHYSICIAN      □ SPIRITUAL CARE PROVIDER      □ MAIN SDM
 □ SOCIAL WORKER      □ NURSE PRACTITIONER      □ DIRECTOR OF CARE

OTHERS (please specify): ____________________________________________________________________________

ITEM CHECK WHEN COMPLETED

<table>
<thead>
<tr>
<th>PRE-DISCUSSION ITEMS</th>
<th>CHECK WHEN COMPLETED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attempt to talk to the resident’s family physician by phone</td>
<td></td>
</tr>
<tr>
<td>Identify emergencies the resident is most likely to experience</td>
<td></td>
</tr>
<tr>
<td>Have a brief huddle prior to the discussion</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>DISCUSSION ITEMS</th>
<th>CHECK WHEN COMPLETED</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clarify the identity and role of the SDM — Script A (Section 8A)</td>
<td></td>
</tr>
<tr>
<td>Prepare the SDM for emergencies — Script B (Section 8B)</td>
<td></td>
</tr>
<tr>
<td>Review the resident’s clinical situation and prognosis — Script C (Section 8C)</td>
<td></td>
</tr>
<tr>
<td>Explain the main alternative philosophical approaches to care — Script D (Section 8D)</td>
<td></td>
</tr>
<tr>
<td>Address the full range of medical options specific for the resident — Script E (Section 8E)</td>
<td></td>
</tr>
<tr>
<td>Conclude the discussion — Script F (Section 8F)</td>
<td></td>
</tr>
</tbody>
</table>

Categorize your judgement of where this resident’s capacity/ability for making medical decisions lies on the 1–4 range from: FULLY INDEPENDENT in making their own medical decisions (1), to SEVERELY IMPAIRED ABILITY to make their own medical decisions (4):

<table>
<thead>
<tr>
<th>FULLY INDEPENDENT</th>
<th>SOMEWHAT INDEPENDENT</th>
<th>MODERATELY IMPAIRED</th>
<th>SEVERELY IMPAIRED</th>
<th>UNCLEAR OR UNKNOWN</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Based on this ACP discussion, please indicate the resident’s wishes about specific treatments:

<table>
<thead>
<tr>
<th>TREATMENT</th>
<th>No, never</th>
<th>Yes, but with conditions</th>
<th>Yes, with no conditions</th>
<th>Undecided</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antibiotics</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeding tube</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer to the emergency room</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Transfer to hospital</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CPR/resuscitation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invasive mechanical ventilation</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>