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1. **OVERVIEW**

A. Advance Care Planning (ACP) refers to a set of processes to help people think about, talk about, and document their wishes for health care in the event they become unable to speak for themselves. It includes designating one or more Substitute Decision Makers (SDMs) who will represent residents’ interests and wishes **if and only if** residents cannot speak for themselves.

B. BABEL stands for “Better tArgeting, Better outcomes for frail ELderly patients”.

C. This workbook walks you through *The BABEL Standardized Approach to Establishing Advance Care Wishes and Preferences for Nursing Home Residents* -- or as we’ll call it for short, BABEL ACP. It is not experimental — it is a quality improvement initiative based on existing best practices and extensive experience.

   - Sections 1-4 contain background material to help you prepare to conduct BABEL ACP discussions.
   - Sections 5-8 contain step-by-step “How To” guides for conducting the ACP discussions.
   - Sections 9-14 contain additional, supplementary materials.

D. BABEL ACP is intended to complement, support and strengthen your current practices, not to replace them.

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

F. BABEL ACP can be used for all nursing home 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 can be obtained from the routinely available assessments done in many nursing homes around the world, using the Resident Assessment Instrument (RAI, also called interRAI or MDS). Such characteristics include: CHESS (Changes in Health, End-stage disease and Symptoms and Signs) score of 3 or greater, leaving more than 25% of food uneaten, presence of heart failure or cancer. Alternative high-risk characteristics can be substituted for these specific ones.

G. This workbook includes details of two, separate kinds of ACP discussions.

   1) Soon after nursing home admission, a brief *Preliminary ACP Discussion* should occur to initially clarify wishes regarding resuscitation and hospitalization. It is “preliminary” in that it does not include the more extensive social and medical contexts that will be available subsequently.

   2) The *Full BABEL ACP Discussion*, should *ideally* occur within 2-8 weeks later, 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. **NOTE: Residents who are medically unstable, or are thought to have a high risk of having a medical emergency event soon, should have the Full BABEL ACP Discussion AS SOON AS POSSIBLE, skipping the Preliminary ACP Discussion.**

H. A **key feature** of BABEL ACP is **SCRIPTS** -- 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. As you gain experience with the BABEL ACP approach and learn its concepts and components, we expect that you will rely less on the scripts.
2. **THE “WEAK LINKS” IN ADVANCE CARE PLANNING**

*BABEL ACP* was designed to **support** your existing ACP practices, not to replace them. The following are common problems in Advance Care Planning that can lead to residents receiving medical care that is not what they had wished to get. Keep them in mind. *BABEL ACP* addresses these problems, and supports proactive and comprehensive discussions about ACP.

**A. Problem 1: The identity of the SDM (Substitute Decision Maker) is unclear:**

1) No SDM has been designated.
2) A designated SDM is unaware she/he is 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 either are unaware that the SDM has been chosen, or challenge the legitimacy of the designated SDM(s).

**B. Problem 2: The SDM role is poorly understood:**

1) Elderly, frail, nursing home residents are often assumed 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.
2) The SDM is unaware of the resident’s preferences and wishes.
3) The SDM cannot—or does not—separate his/her own preferences and wishes from those of the resident.

**C. Problem 3: Insufficient information was provided to the resident and SDM to understand the following items:**

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) The expected benefits and potential harms of specific care interventions and medical treatments.
4) That it is often possible to address future medical challenges or symptoms while the resident remains in the nursing home.

**D. Problem 4: Failure by nursing home staff to provide needed information and reassurance during a health crisis:**

1) In the crisis, staff are unable to quickly find and access documentation about previously expressed ACP wishes.
2) The mistaken idea that hospitals do “something” while nursing homes do “nothing”, or that hospitals always provide better treatment than what can be provided in the nursing home.
3) Failure to help the resident and SDM understand that effective symptom and pain management can almost always be provided in the nursing home.
4) The challenge of conveying clinical information that may be uncertain, while also ensuring that the resident and SDM recognize that the nursing home team is competent.
5) Failure to remind the SDM of the resident’s care wishes, and—when relevant—reassuring the SDM that the care desired by the resident can be provided in the nursing home.

*THESE ISSUES OFTEN ARISE DURING EVENINGS OR NIGHTS*
3. **GENERAL PRINCIPLES: 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 nursing home staff performing this task.

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

B. ACP discussions are best arranged and organized in advance, not happening spontaneously.

C. Direct involvement of physicians is strongly encouraged but not always feasible. A **BABEL Pre-Discussion Guide for Physicians** has been created to inform physicians on the BABEL approach, and can be used as a reminder before ACP discussions occur for a resident. A copy of this document is in Section 13 of this workbook (p.54-55).

D. Review the **BABEL ACP Discussion Guide for Staff** in Section 12 (p.51-53).

E. Before conducting ACP discussions, the nursing home 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.

F. The ACP discussion 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 a main SDM).

G. Discussions should be held in a quiet, private, and comfortable location.

H. The SDM(s) should preferably be present in person, though telephone or video electronic presence is acceptable (e.g. ZOOM, Skype, Facetime).

I. Unless the resident is completely unable to participate, primarily speak with the resident, not the SDM.

J. Use simple language (aim for a Grade 8 level), avoiding jargon or medical abbreviations. For example: say **heart failure**, not **CHF**; say **breathing machine** not **ventilator**; say **insert a breathing tube** not **intubation**. Since lay people usually do not let you know when they don’t understand medical terminology, it is our job to make sure that they do understand by using common language, and by pausing periodically to ask if everyone understood what was said.

K. If the residents and/or SDM(s) understanding of English is difficult, have a translator present. The translator, if possible, should be a certified medical translator, **not** a friend, family member, or available lay person. If such a translator is not available, consider rescheduling.

L. Be sensitive to the possible presence of underlying family conflict, that may cause the resident to feel coerced into expressing specific care wishes. Nursing home staff 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. In such occurs, the nursing home team may choose to discretely explore these dynamics and spend more time to better understand the resident’s goals and wishes, and to assess which family members demonstrate alignment and respect for these, and who thus could be suitable SDMs. It may be preferable, in some cases, to get a better “lay of the land” before proceeding to a larger meeting that might potentially be uncomfortable for the resident.
4. **GENERAL PRINCIPLES: ASSESSING RESIDENTS’ CAPACITY TO MAKE THEIR OWN MEDICAL DECISIONS**

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

B. Capacity can change over time. It can worsen after certain conditions such as a stroke. It can improve. It can even fluctuate hour to hour, as is common with delirium.

C. **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).

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

E. In BABEL ACP, **assessing capacity is integrated into the discussions.** Instead of using a formal tool to evaluate the resident’s capacity for understanding and making known his/her wishes regarding medical care, capacity is evaluated as “part and parcel” of the ACP discussion. This is based on whether the personnel leading the discussion and the SDMs judge that the resident understands, and appears to be making rational choices consistent with his/her beliefs and philosophy.

F. After key steps, pause and ask the resident to share his/her understanding of the discussion that just occurred. If the resident’s responses are coherent, then conclude she/he has capacity. Remember that even if she/he isn’t fully capable, it is still often possible for the resident to express what is important to her/him, his/her philosophy of life, and of end-of-life preferences.

G. It is important to recognize that even residents with cognitive dysfunction can and must be allowed to express their wishes in relation to their care and end-of-life preferences, regardless of whether they are ultimately found to be incapable of understanding and making known their wishes regarding medical care. **THE RESIDENT’S WISHES ALWAYS MATTER.**
5. THE PRELIMINARY ACP DISCUSSION

Make sure that you are familiar with the principles in Sections 3 and 4 (p.4-5).

A. About the Preliminary ACP Discussion

1) The 4 purposes of this discussion are to:
   - Determine the resident’s wishes regarding who will be his/her SDM.
   - Determine the resident’s preliminary wishes regarding resuscitation (CPR).
   - Determine the resident’s preliminary wishes regarding transfer to emergency or hospital.
   - Provide the resident and others with BABEL ACP materials, and arrange a specific time and date to follow-up and have the Full BABEL ACP Discussion.

2) The Preliminary ACP Discussion is meant to address these 4 issues -- but without the complete medical and philosophical context included in the subsequent Full BABEL ACP Discussion. The reason for doing this is that the extensive stakeholder input that helped us design BABEL ACP indicated that it is very important to get a first understanding of these items very soon after a resident enters the nursing home -- but that at the same time they need to be revisited after the nursing home personnel and physician acquire a better understanding of the resident and her/his medical situation.

3) What is meant here by “preliminary” is that thoughts and wishes from this discussion will be re-visited during the subsequent Full BABEL ACP Discussion.

4) For whom, and when should the Preliminary ACP Discussion should occur?
   - Residents newly admitted to the nursing home -- as soon as possible after admission, but within one week if at all possible.

B. Preparing for the Preliminary ACP Discussion

1) Arrange in advance to meet in person with the resident, SDM if one has been chosen, and other family or friends who the resident (or SDM) wants present.
   - In arranging the meeting, tell the resident and other participants that the purpose of the meeting is to BEGIN talking about the resident’s wishes for care while she/he is living in the nursing home.
   - Let everyone know in advance that this meeting should take about 20-30 minutes.
   - If possible, the resident’s nursing home physician should participate in this discussion.

2) Identify existing documentation related to previously expressed advance care preferences.

3) Determine whether a SDM has already been designated, can be contacted, and is available.

4) Remember that capacity assessment is embedded with the discussion process (p.5, Section 4). After key steps, pause and ask the resident to share his/her understanding of the discussion that just occurred. If the resident’s responses are coherent, then conclude she/he has capacity. Remember that even if she/he isn’t fully capable, it is still usually possible for the resident to express what is important to her/him, his/her philosophy of life, and of end-of-life preferences.
C. Conducting the Preliminary ACP Discussion

1) Prior to joining the resident/SDM, the nursing home team (including the physician, if present) should have a brief huddle to prepare. This huddle serves the following purposes:

- Ensure a shared understanding of the resident’s clinical status, likely clinical trajectory, and outcomes. This includes reviewing the diagnoses that affect the resident.
- Remind the nursing home staff and physician (if present) about BABEL ACP.
- If the physician is present, she/he should receive a copy of the BABEL Pre-Discussion Guide for Physicians to serve as a reminder (Section 13, p.54-55).
- The nursing home staff should review the BABEL Advance Care Planning: Discussion Guide for Staff (Section 12, p.51-53).
- Provide an opportunity to review documentation of prior ACP discussions and expressed wishes.

2) The next section (Section 6) contains SCRIPTS for the Preliminary ACP Discussion, and should be viewed as suggestions on how to incorporate best practices into the ACP discussion.

Scripts are coded with different fonts and colors:

- Text in [GREY boxes with dark grey lines] is information for you, providing context & prompts to direct the discussion.
- Suggested words to say, are in italics.
- Underlined items are VARIABLES that you will need to supply as you speak depending on whether you are speaking to the resident or the resident’s SDM.
- Since sometimes you will be speaking to the resident, and other times you’ll be speaking to the Substitute Decision Maker, the VARIABLES within the scripts include things like this:

  - “We are glad you have invited people close to [you] {resident’s name} to give support.”

- Note the text: [you] {resident’s name}. The first part is in square brackets and contains what you would say when talking to a resident. The second part is in curly brackets and contains what you would say when mainly talking to a Substitute Decision Maker.

- So, when talking with the resident you would say: “We are glad you have invited people close to you to give support.”

- But when talking to the Substitute Decision Maker (Mr. Jones) you would say something like: “We are glad you have invited people close to Mrs. Jones to give support.”

- Sometimes you’ll have to adjust wording ‘on the fly’. For example, for a text saying “Have [you] {resident’s name} decided” the words are obviously “HAVE you decided” if talking to the resident, but “HAS Mrs. Jones decided” if talking to the Substitute Decision Maker.
6. **SCRIPTS FOR THE PRELIMINARY ACP DISCUSSION:**

This section contains the six Scripts of the *Preliminary ACP Discussion*. They should be viewed as *suggestions* on how to incorporate best practices into the ACP discussion.

**SCRIPT 6A. Introductions and State the Purpose of Preliminary ACP Discussion**

- **Hello, my name is** NAME **and I am a** POSITION **here.**

- **We are glad that you have invited people close to** [you] [resident’s name] **to provide help and support with the important topics that we will talk about.**

- Have everyone introduce themselves.

- **This should be a short discussion today; 20-30 minutes.**

- **What we hope to do is begin to learn about** [you] [resident’s name], **and** [your] [her/his] **wishes about two key parts of medical care while here in the nursing 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 followup meeting, we will have a better idea about** [your] [resident’s name] **health, so we can better revisit the care wishes made known to us today, and make the additional ones that are needed.**

- **Move on to Script 6B.**
SCRIPT 6B. Confirm the Substitute Decision Maker (SDM)

- Now we want to confirm {your} {resident’s name} choice to speak for {you} {her/him} if {you} {she/he} become/becomes too sick to speak for {yourself} {herself/himself}.

- We call these “Substitute Decision Makers”. This is one of the most important decisions one can ever make.

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

- But even so, it is important to spell out the following things about the role of the SDM:

- If a medical crisis occurs, it is important that {your} {resident’s name} goals and wishes are respected, and the Substitute Decision Maker commits to carrying these out if and when the time comes.

- That’s why we need to have Substitute Decision Makers be part of these discussion, so that everyone is on the same page, understands the achievable goals, and knows what {you} {resident’s name} would want if this, that, or the other thing, happens medically.

- Have/has {you} {resident’s name} identified who will be the Substitute Decision Maker? If not, it will be necessary to think about who this would be.

-PAUSE.

-Open the conversation to the resident and the family before moving onto to PART C.

-Ensure that the resident identifies the SDM(s), and that the SDM(s) accept this responsibility.

-Though generally all goes well, nursing home staff 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 and disrupts the meeting and causes distress to the resident, consider stopping and rescheduling the meeting.
SCRIPT 6C. Address Preliminary Preferences Related to CPR/Resuscitation

✦ Next, we want to talk about a specific medical emergency -- if we find [you] {resident’s name} without a heart beat, or not breathing.
✦ When that happens to someone, unless we know that the person does not wish 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?

-PAUSE. Invite thoughts, and comments from the SDM, resident, and others in the group before moving on. Consider using the survival illustration for cardiac arrest in nursing homes (p.45).

✦ It's important to know about this, because it’s not like on television. On TV, most people in this situation live, but in real life only about 3 in 100 nursing home residents who get CPR are alive 30 days later. While we cannot be certain what would happen to [you] {resident’s name}, 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] {resident’s name} do/does not wish to undergo CPR, we will make sure that [you] {resident’s name} will be comfortable and be able to pass away peacefully.
✦ In other words, if [your] {resident’s name} heart stops, would [you] {resident’s name} want it to be treated as a medical emergency and do CPR and other things to try and get the heart restarted, or would [you] {resident’s name} prefer to be allowed to pass away peacefully?
✦ How would this fit with [your] {resident’s name} goals at this time?

-Make sure to check that the resident and SDM 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 his/her reasoning for the choice expressed. Discuss as needed.
-Be clear, direct, and give the resident and SDM time to understand the information 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 goals and wishes (or as expressed by the SDM if the resident is not able to) regarding CPR have been heard and understood by all who are present.
-Clearly repeat what the resident indicated regarding CPR and resuscitation:

✦ So, if I understand correctly, if one of our nurses were to find [you] {resident’s name} without a heart beat or not breathing, [you] {she/he} would prefer that we REPEAT YOUR UNDERSTANDING OF THE RESIDENT’S WISHES ABOUT RESUSCITATION.

-DOCUMENT this wish regarding CPR/resuscitation in the resident’s chart.
-Answer any further questions as needed. Move onto Part D.

*NOTE: 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 and refer to the guidance given on the website listed on p.33
SCRIPT 6D. Address Preliminary Preferences for Emergency Department and Hospital transfers

We want to discuss what to do if [you] {resident’s name} got sicker -- to be transferred to emergency or the hospital, or to stay here and get treated at the nursing home.

Unless we know otherwise, we will call an ambulance and send [you] {resident’s name} to emergency or the hospital. But we will always ask about [your] {resident’s name} preference for being transferred when it happens.

Sometimes, going to the hospital is a good idea. Though many conditions can be treated in the nursing home just as well as in the hospital, some treatments are only available in the hospital.

But for some nursing home residents, some 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] {resident’s name} preferences as of now.

What are [your] {resident’s name} thoughts about this? How would this fit with [your] {resident’s name} goals and wishes for [yourself] {herself/herself}?

In general, if [you] {resident’s name} got sicker, would [you] {she/he} wish to go to the hospital, or remain at the the nursing home and do what we can here?

-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 and other family members at the meeting understand. Answer questions as needed.

-Use “check back” (having the resident/SDM explain in his/her own words) to assess their understanding of their clinical state and possible course.

-When the resident and/or the SDM appear to have understood this, summarize the results of the discussion.

-Clearly repeat what the resident said about transfer to emergency department or hospital:

So, if I understand correctly, if [you] {resident’s name} were to get sicker, [your] {her/his} wish would be that we REPEAT YOUR UNDERSTANDING OF THE RESIDENT’S WISHES ABOUT SUCH TRANSFERS.

-DOCUMENT this wish regarding acute transfers in the resident’s chart. Move onto Part E.
SCRIPT 6E. Conclude, and Arrange the Followup Full BABEL ACP Discussion

- The initial priorities of CPR and hospitalization have now been addressed. There may be other medical treatments that might be considered for this resident, and that also have implications on the 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 particularly high risk of having a medical emergency soon.

- The nursing home team should now call the meeting to a close, and ensure that the discussion is documented, including all ascertainment of capacity and resident choices.

☀ We have done what we needed to do today. We had a good meeting. Thank you all for coming.

☀ We addressed whether [you] {resident’s name} would want to be hospitalized if things got worse, and what to do if [your] {resident’s name} heart stops.

☀ Remember, this discussion is for [you] {resident’s name} to express [your] {her/his} wishes. If these decisions change, let us know.

☀ We still need to talk about [your] {resident’s name} wishes regarding all the other medical care issues that might arise in the future.

➢ To do that, we want to arrange to have another meeting in no more than 2 to 6 weeks from now. At that meeting, we will have a better idea about [your] {resident’s name} health, so we can better help regarding the wishes expressed today, and the additional ones that still need to be addressed.

➢ To help everyone get ready for that discussion, we have a small pamphlet to give to you. ALSO, there are some other materials about Advance Care Planning here in the nursing home. The one that many people find useful is the one called “SpeakUp”.

- Hand out copies of the ACP pamphlet (BABEL Advance Care Planning: Getting What You Want From the Care We Provide).

- Show them where in the nursing home they can obtain other materials on ACP.

- Provide resident and SDM with any other documentation that may be relevant to the specific diagnoses (e.g., heart failure, Parkinson’s disease).

- Ensure to DOCUMENT the date/time has been set for the next ACP discussion. If there are still arrangements to be made for it, follow up on them soon.

- DOCUMENT (be as specific as possible) whether, during this discussion, the resident:
  • Had full capacity for understanding/making his/her wishes regarding medical care, OR
  • Had partial capacity for understanding/making his/her wishes regarding medical care, OR
  • Lacked capacity for understanding/making his/her wishes regarding medical care

END OF THE PRELIMINARY ACP DISCUSSION
THE FULL BABEL
ACP DISCUSSION
7. **THE FULL BABEL ACP DISCUSSION**

*Make sure that you are familiar with the principles in Sections 3 and 4 (p.4-5).*

A. **About the Full Babel ACP Discussion**

1) This discussion should occur if at all possible within 2-4 weeks after the *Preliminary ACP Discussion*. It should have been arranged at the end of that *Preliminary ACP Discussion*, or shortly thereafter.

2) If a *Preliminary ACP Discussion* did not occur, or occurred awhile ago, then arrange this *Full BABEL ACP Discussion* to happen as soon as possible.

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

B. **Preparing for the Full BABEL ACP Discussion**

1) In advance of this discussion, attempt to contact the resident’s family physician (this usually is different from the nursing home physician) by phone, letting her/him know that an ACP discussion is going to take place in the nursing home, and asking her/him to share information about the resident and SDM, medical history, prognosis, and prior ACP discussions.

2) Arrange *in advance* to have the Full BABEL 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 nursing home physician.
   - In arranging the meeting, specifically 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 she/he is living in the nursing home -- that at this meeting we will *discuss the full range of possible medical situations that might occur and identify the resident’s wishes about the medical choices that can arise*.
   - Let everyone know in advance that may take 60 minutes or maybe even more.
   - If possible, the resident’s nursing home physician should participate in this discussion.

3) Identify existing documentation related to advance care preferences.

4) Remember that *capacity assessment is embedded with the discussion process* (p.5, Section 4). After key steps, pause and ask the resident to share his/her understanding of the discussion that just occurred. If the resident’s responses are coherent, then conclude she/he has capacity. Remember that even if she/he isn’t fully capable, it is still usually possible for the resident to express what is important to her/him, his/her philosophy of life, and of end-of-life preferences.
C. Identify Medical Emergencies This Resident is Most Likely to Experience

1. A key part of this 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 a main focus of the Full BABEL ACP discussion.

3. So, before this discussion, the nursing home staff 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 in this, even if the resident’s physician is not going to be able to be present at this discussion with the resident and SDM, the nursing home staff who will conduct the discussion should contact the nursing home physician in advance to inform themselves about the most likely medical emergencies that should be discussed.

4. The following Table 7C (p.17) shows medical situations that commonly arise in nursing home residents, with additional information for specific clinical situations available in Sections 9 and Section 10 (p.29-44). We do NOT intend for you to discuss all of these with all residents in the Full BABEL ACP Discussion. And the list is not comprehensive -- there are other medical situations that may arise that are not on this list.

5. The Full BABEL ACP discussion is meant to discuss those situations which are most likely to occur for the specific resident. So, before beginning the Full BABEL ACP discussion, the team (including the physician, if present) should all know which medical issues are MOST likely to arise for this specific resident.

6. ★★ In discussing any given medical situation, it is extremely important to explain what the resident should expect of their physical and mental condition IF and AFTER they survive treatment. This is vital, because we know that most people use precisely this information to deciding on their wishes about potential treatments.

7. 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, being realistic but not acting as if the only possibilities are death or full recovery -- because many frail people survive with significant worsening of their physical or mental condition, and we must speak about that when appropriate.
<table>
<thead>
<tr>
<th>TYPE OF URGENT SITUATION</th>
<th>COMMONLY OCCURS WITH</th>
<th>POSSIBLE TREATMENT OPTIONS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infection</td>
<td>Almost any chronic disorder, Limited mobility, Frailty</td>
<td>Options available in nursing home: - Oral antibiotics  Options requiring hospitalization: - Intravenous antibiotics</td>
</tr>
<tr>
<td>Pneumonia</td>
<td>COPD, Other chronic lung problems, Cancer, Limited mobility, Frailty</td>
<td>Options available in nursing home: - Supportive care; Oxygen - Oral antibiotics  Options requiring hospitalization: - Intravenous antibiotics - Non-invasive mechanical ventilation (e.g. CPAP, BiPAP) - Artificial life support (invasive mechanical ventilation)</td>
</tr>
<tr>
<td>Aspiration</td>
<td>Neurologic disorders, Dementia, Frailty</td>
<td>Options available in nursing home: - 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</td>
</tr>
<tr>
<td>Falls, fractures</td>
<td>Advanced age, Osteoporosis, Neurologic disorders, Dementia, Frailty</td>
<td>Options available in nursing home: - Pain medicines; Splinting; Supportive care  Options requiring hospitalization: - Intravenous pain medicines - X-rays; Casting; Surgery (including for relief of severe pain)</td>
</tr>
<tr>
<td>Sudden weakness or numbness</td>
<td>Stroke, Bleeding in brain</td>
<td>Options available in nursing home: - Supportive care  Options requiring hospitalization: - Brain imaging tests (e.g. CT or MRI) - Intravenous medications - Surgery</td>
</tr>
<tr>
<td>Shortness of breath</td>
<td>Any heart disorder (heart failure, ischemic heart disease, others), Any lung disorder (COPD, asthma, others)</td>
<td>Options available in nursing home: - Supportive care; Oxygen - Narcotics, other oral medicines  Options requiring hospitalization: - Intravenous medicines - Non-invasive mechanical ventilation (e.g. CPAP, BiPAP) - 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), Very near the end of life</td>
<td>Options available in nursing home: - Feeding assistance; Diet modification - Allow resident to eat, or accept that they will not Nasogastric feeding tube (short-term solution only) Intravenous administration of subcutaneous fluids  Options requiring hospitalization: - Surgically-inserted feeding tube (PEG/PEJ) - Intravenous nutrition</td>
</tr>
</tbody>
</table>
D. Conducting the Full BABEL ACP Discussion

1) Prior to joining the resident/SDM, the nursing home team (including the physician, if present) should have a huddle to prepare. This huddle serves the following purposes:

- Identify AND BE PREPARED TO DISCUSS the medical situations that are most likely to arise in this particular resident. While it is mainly THOSE situations that are to be discussed -- note that one of the aims of this discussion is to identify wishes regarding the following 6 items for all residents: antibiotics, feeding tubes, transfer to Emergency, hospitalization, CPR/resuscitation, and use of invasive mechanical ventilation; these 6 items are listed on the Checklist for this Discussion (p.56).

  • Ensure a shared understanding of the resident’s clinical status, likely clinical trajectory, and outcomes. This includes reviewing the diagnoses that affect the resident.
  • Remind the nursing home staff and physician (if present) about BABEL ACP.
  • If the physician is present, she/he should receive a copy of the BABEL Pre-Discussion Guide for Physicians to serve as a reminder (Section 13, p.54-55).
  • The nursing home staff should review the BABEL Advance Care Planning: Discussion Guide for Staff (Section 12, p.51-53).
  • Review documentation of prior ACP discussions and expressed wishes.

2) Provide the resident and SDMs with the pamphlet BABEL Advance Care Planning: Getting What You Want From the Care We Provide. Also, direct them to the online/written library of additional resources, including the Speak Up booklet, and other resources listed on p.53 of this workbook.

3) The next section (Section 8) contains SCRIPTS for the FULL BABEL ACP Discussion, and should be viewed as suggestions on how to incorporate best practices into the ACP discussion. Scripts are coded with different fonts and colors:

  • Text in GREY boxes with dark grey lines is information for you, providing context and prompts to direct the discussion.
  • Suggested words to say, are in italics.
  • Underlined items are VARIABLES that you will need to supply as you speak, depending on whether you are speaking to the resident or the resident’s SDM.
  • Since sometimes you will be speaking to the resident, and other times you’ll be speaking to the Substitute Decision Maker, the VARIABLES within the scripts include things like this:
    -“We are glad you have invited people close to [you] {resident’s name} to provide support.”
    -Note the text [you] {resident’s name}. The first part is in square brackets and contains what you would say when talking to the resident. The second part is in curly brackets and contains what you would say when talking to the Substitute Decision Maker.
    -So, when talking with the resident you would say: “We are glad that you have invited people close to you to provide support.”
    -But when talking to the Substitute Decision Maker (Mr. Jones) you would say something like: “We are glad that you have invited people close to Mrs. Jones to provide support.”

4) The CHECKLIST on page 56 may be used prior to and during the discussion to ensure you have considered all recommended elements, and to document key wishes regarding care.
Hello, my name is NAME and I am a/the POSITION here. We are here to learn more about [your] {resident’s name}‘s thoughts and wishes about medical care while [you] {she/he} is 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.

- Have everyone introduce themselves.
- Provide the attendees with copies of the BABEL Resident Pamphlet if they have not yet received one.
- If you were successful in contacting the resident’s family doctor before this first ACP discussion, mention that this was done.

First we want to confirm who [you] {resident’s name} chose to speak for [you] {her/him} if [you] {she/he} becomes too sick to speak for [yourself] {herself/himself}. We call this the “Substitute Decision Maker”. This is one of the most important decisions one can ever make.

- This decision may have already been made and documented prior to this discussion. You may refer to Script 6B on Page 10 for guidance.
- The goal is to confirm the SDM and review the role of the SDM with all attendees.

What we want to do now is make sure that everyone understands that the job of Substitute Decision Makers is to help us understand what [you] {resident’s name} would wish for us to do, or not do, if [you] {she/he} get too sick to tell us.

It is critical to understand the job of the Substitute Decision Maker -- it is to tell us what care [you] {resident’s name} would wish to have done -- NOT what the Substitute Decision Maker would want done.

If [you] {resident’s name} becomes very ill and is 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] {resident’s name}.

It is important that the Substitute Decision Maker knows what [you] {resident’s name} would want if a medical crisis arises, respects [your] {her/his} goals and wishes, and commits to respecting them if and when the time comes.

That’s why we need to have Substitute Decision Makers be part of these discussions, so that everyone is on the same page, understands the achievable goals and wishes, and knows what [you] {resident’s name} want/wants if this, that or the other thing happens medically.

>>>Script 8A Continues on Next Page<<<
- PAUSE.
- Open the conversation with the resident, SDM and invitees before moving on to the next Script.
- Ensure that the resident identifies the SDM, and that the SDM accepts this responsibility.
- Though generally all goes well, nursing home staff 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.
SCRIPT 8B. Prepare the Substitute Decision Maker for Emergencies

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

🌟 Now we want to talk about what Substitute Decision Makers, like you, should expect if an emergency happens.

🌟 Emergency situations DO happen, and RESIDENT NAME may then be too sick to decide about the treatment options. If THAT happens, a team member from the nursing home will call you, and you will then have the responsibility of helping us understand what RESIDENT 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 pad and pen 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 nursing 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 what we have discussed in meetings we have had about RESIDENT’S NAME wishes if such a thing occurred.

🌟 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 following question. “Based on your previous discussions with the RESIDENT NAME, and what you know about HER/HIS values, beliefs, wishes and health, what would SHE/HE 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, as Substitute Decision Maker, 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.

- PAUSE.

- Invite thoughts, responses and commentaries from the SDM, the resident, and others in the group before moving onto Part C.

- Document this discussion, being as specific as possible.
SCRIPT 8C. Review the Resident’s Current Clinical Situation and Prognosis

 عشر، نحن نريد أن نتأكد جميعًا من أنه كلنا على الصفحة نفسها حول [اسم السماح] حالته الصحية الحالية والوضع الطبي.

 أحول معلوماتكم عن [اسم السماح] حالته الصحية الحالية.

- حدس السماح (أو SDM إذا كان السماح لا يستطيع القيام بذلك)، وصف الوضع الطبي الحالية.
- استجابة أي أسئلة. إذا لم يكن السماح أو SDM أو العائلة متأكدين بشكل كامل من الوضع الطبي، قل مرة أخرى عن الوضع الطبي. استخدام لغة بسيطة، ولا تستخدم الجargon أو الألفاميات. هذا يجب أن يتم من قبل الطبيب، إذا كان موجودًا.
- تذكر أن قدرتك على تقديم توضيح واضح إلى النتائج المرجوة هي جزء من كيفية تقييم السماح القدرة على فهم وصياغة طلبات الرعاية الطبية الموجهة.

 ونحن نريد أيضًا أن نتأكد جميعًا من أن نفهم ما [اسم السماح] وضع طبي يعني من الجوانب المحددة.

- نفترض أن السماح [اسم السماح]، ماذا تعتقد أنه يعني؟
-تجنب استخدام كلمة "التنبؤ" -- كثيرًا ما لا يفهم هذا المصطلح. بدلاً من ذلك، تحدث عن "ما هو المستقبل بالنسبة لك" أو شيء مشابه.
-تأكد من أن السماح و SDM يدركون:
  - حالات المرض الحالية، مثل القلب التحتيف، السرطان، التشوهات العصبية
  - حالات المرض الحالية التي تشير إلى الاحتمالية زائدة من حدوث حالة طبية خطيرة في فترة زمنية أقصر [تنبؤ ضعيف]
  - الأمور الأخرى التي تشير إلى تنبؤ ضعيف (مثل الشهية السيئة).
- IF the resident is FRAIL، قم بتذكير السماح، إذا كان ذلك ضعيفًا، أنه بالإضافة إلى الحالات الطبية المحددة، ضعف يتصل بشكل فعال إلى تقليل التكلفة، فرصة أصغر للربح من العلاجات الطبية، وفرصة أكبر للعثور على مضاعفات من العلاجات الطبية. يمكنك القول باستخدام الرسم البياني الموضح على ق.46 إذا كان فراغ ضعيفًا موجودًا.
- استجابة أي أسئلة قبل التوجه إلى النص التالي.

- نفترض أن السماح [اسم السماح]، ماذا تعتقد أنه يعني؟
-تجنب استخدام كلمة "التنبؤ" -- كثيرًا ما لا يفهم هذا المصطلح. بدلاً من ذلك، تحدث عن "ما هو المستقبل بالنسبة لك" أو شيء مشابه.
-تأكد من أن السماح و SDM يدركون:
  - حالات المرض الحالية، مثل القلب التحتيف، السرطان، التشوهات العصبية
  - حالات المرض الحالية التي تشير إلى الاحتمالية زائدة من حدوث حالة طبية خطيرة في فترة زمنية أقصر [تنبؤ ضعيف]
  - الأمور الأخرى التي تشير إلى تنبؤ ضعيف (مثل الشهية السيئة).
- IF the resident is FRAIL، قم بتذكير السماح، إذا كان ذلك ضعيفًا، أنه بالإضافة إلى الحالات الطبية المحددة، ضعف يتصل بشكل فعال إلى تقليل التكلفة، فرصة أصغر للربح من العلاجات الطبية، وفرصة أكبر للعثور على مضاعفات من العلاجات الطبية. يمكنك القول باستخدام الرسم البياني الموضح على ق.46 إذا كان فراغ ضعيفًا موجودًا.
- استجابة أي أسئلة قبل التوجه إلى النص التالي.
Before we go on and talk about specific medical treatments, we want to explain the general types of approaches to medical care. Call this the different “philosophies of care” that [you] {resident’s name} 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.

But before we talk about the main options, there are two things to consider that often influence people’s wishes for their medical care:

- First -- is that 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] {resident’s name}.
- Second -- is that 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 would the future holds -- we do know that this fact is important to most peoples’ wishes about their care.

- PAUSE. Answer any questions.
- Next, you will describe the 3 main approaches to medical care.

There are 3 MAIN APPROACHES TO MEDICAL CARE in nursing homes that I will explain.

We will need to understand which one fits best with [your] {resident’s name} 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] {resident’s name} from whatever happens.

These may include: using antibiotics for a serious infection, such as pneumonia; transfer to hospital for treatments that can’t be done in the nursing home; trying to get the heart restarted if it stops; using artificial life support if needed; surgery if needed. And there are lots of other things we are able to do.

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.

>>>Script 8D continues on the next page<<<
- Use “check back” (having the resident/SDM explain in his/her own words) to assess their understanding of the “Try Everything to Help me Live Longer” approach.
- Move on to describing the second approach.

- The SECOND choice is called “COMFORT CARE”.
- The idea is we know AND ACCEPT that death is coming. We do not rush it, but we don’t try and delay it either. We accept it. WHENEVER it happens.
- BUT COMFORT CARE IS CARE. We use whatever medicines or treatments are needed to make sure that the person is comfortable, no matter what happens, and no matter how long they may have.
- Even when we can’t cure or fix a medical problem, we are very good at making sure that the person is comfortable. And we can almost always do that right here in the nursing home.
- This choice is also called ALLOWING A NATURAL DEATH. It is not euthanasia, or killing the person. 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?

- Use “check back” (having the resident/SDM explain in his/her own words) to assess their understanding of the “Comfort Care” approach. Answer any questions. Once that is done, proceed onwards.

- Lastly, [you] {resident’s name} may feel that neither “Try Everything to Help Me Live Longer” or “Comfort Care” are quite right. So the THIRD option is in between those two. We call it the “MENU OF POSSIBLE TREATMENTS”.
- The idea is that there might be some types of medical care that [you] {resident’s name} might wish to accept, and others that [you] {she/he} might NOT wish to accept.
- For example, [you] {resident’s name} might wish to accept treatments that can be given in the Nursing Home, but not want to go to Emergency or Hospital for treatments that cannot be given here.
- Or [you] {resident’s name} might wish to accept treatments here AND agree to go to Emergency or Hospital for certain treatments we cannot give here at the nursing home.

>>>Script 8D continues on the next page<<<
Let me tell you about a choice made by many people in Nursing Homes who are not comfortable with either “Try Everything to Help me Live Longer” or “Comfort Care”.

- If something big and life-threatening happens — like a stroke or heart attack — they wish to stay in the nursing home and just be kept comfortable.
- But for a medical problem that is NOT life threatening, and that we cannot treat in the Nursing Home, they wish to go to Emergency or Hospital for a short time only — to get it taken care of — and then come back to the Nursing Home instead of staying in hospital for a longer time.

- An example might be to go and get a cut stitched up after a fall that leads to a bleeding cut. Or to get an X-ray and a cast for a broken bone. Or, some intravenous fluids to help recover from severe diarrhea. But artificial life support in the hospital would be off the table.

- Use “check back” (having the resident/SDM explain in his/her own words) to assess their understanding of the “Menu of Possible Treatments” approach.

So, we have explained the three main types of care options. They are: (1) Try Everything to Help me Live Longer, (2) Comfort Care, and (3) Menu of Possible Treatments.

Do you want me to go over any or all of them again?

- Repeat explanations, if requested. Answer any questions.

- If you aren’t sure, It is NOT necessary for you to tell us which of the 3 choices would be [your] {resident’s name} wish.

- But it will be helpful to keep these three options in mind and which one fits best with [your] {resident’s name} beliefs and wishes.

- IF you DO know which of these is right, feel free to tell us now.

- Please remember that no matter which of these 3 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] {resident’s name} views, wishes and preferences, so it will be easier when an emergency happens and a decision is needed.

- 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).
MAKE CERTAIN TO READ THIS MATERIAL -- IT IS VERY HELPFUL
- This part of the Full BABEL Discussion is where it has all been leading.
- Because each resident’s medical issues are different, you will notice that there are no specific suggestions for the words to use for most of this.
★★ While the focus here is understanding getting at 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 on Page 22.
  ➢ 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 she/he survives, breathing problems and disability will not be better than usual, and may well 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 she/he desires, within the realm of what is achievable.
- If the resident indicated she/he prefers 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] {resident’s name} medical situation.

- Now, describe in simple language the MOST LIKELY, SEVERE medical situation that might arise for this specific resident. Explain to the resident and others why it is likely.
- Then AS SIMPLY AS POSSIBLE describe the possible treatments for the situation, and the possible outcomes of the treatments -- refer to Table 7C on Page 17 of this workbook, with additional information for specific clinical situations available in Sections 9 and Section 10 (p.29-44).
- If the resident/SDM indicated that the wished-for approach to care is COMFORT CARE, then the options appropriately center purely around ensuring comfort.
★★ If resident does NOT prefer Comfort Care, then it is important to talk about:
(i) treatments that can be provided in the Nursing Home, versus (ii) treatments which can only be provided by being transferred to Emergency or Hospital.
- Restate and confirm the wishes expressed to make sure everyone is on the same page. DOCUMENT THEM.

>>Script 8E continues on the next page<<<
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.

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

Here is a script example: “We’ve already talked about your weak heart. Sometimes, people with weak hearts fall and break their hips. 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.”

Regardless of which specific medical issues you discussed for this resident, ALL residents should have had the opportunity to clearly express wishes regarding the following 6 items below. IF and WHICH CIRCUMSTANCES the residents would wish for:

1) Antibiotics for infection
2) Artificial feeding tube
3) Transferred to Emergency
4) Hospitalized
5) Resuscitation/CPR
   {NOTE: if the resident indicated that she/he would NOT want transfer to Emergency (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 she/he would NOT want transfer to Emergency (item#3) or Hospitalization (item#4), then this item should automatically be “No”}.

Note: One possible way to record these wishes is to use the Checklist on p.56, which uses these 4 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 of these to make sure everyone is on the same page.

DOCUMENT THEM.
SCRIPT 8F: Conclude the Discussion

- The nursing home team now calls 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.

* Today was good and we all now have a better understanding of [your] {resident’s name} wishes for medical care as of now.

* Remember, it is OK for people to change their minds. If and when an emergency happens, the treatment choices will be discussed, but knowing [your] {resident’s name} wishes at this point will help us to have these conversations in the future.

* If [your] {resident’s name} medical conditions changes, [your] {her/his} wishes may change too, and we will want to go over these things again. Also, we have a policy here of repeating these discussions at least once a year.

* Thank you all for coming today.

DOCUMENT (be specific) whether, in your judgement, the resident demonstrated:

- Full capacity to understand/express his/her wishes regarding medical care, OR
- Partial capacity to understand/express his/her wishes regarding medical care, OR
- Lacks the capacity to understand/express his/her wishes regarding medical care.

END OF THE GENERAL PORTION OF THE FULL BABEL ACP DISCUSSION

(Scripts and Other Information for Special Clinical Situations Follow)
9. 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 suffering the specific clinical situation discussed. However, with a little adjustment of the words, you can equally well 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 (e.g. see Table 7C on p.17).

- As for the other Scripts in this workbook, in using these you should be familiar with the general principles in Section 3 and Section 4 (p.4-5). In particular, if the physician is present, she/he should lead these Script-based discussions.
1) Neurologic disorders and pneumonia are both common in long-term care residents.
   - Pneumonia is infection of the lungs.
   - Pneumonia is common in this stage of life, and is often the final illness and immediate cause of death in nursing home residents.
   - The most common neurologic disorders in nursing home residents are: dementia, stroke, and Parkinson’s Disease.
   - Others neurologic disorders include: Amyotrophic Lateral Sclerosis (ALS), Multiple Sclerosis, 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, and blood clots to the lungs (pulmonary embolism).

4) There is an important relationship between neurologic disorders and pneumonia – it is **ASPIRATION**: When saliva and 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:
   - Aspiration
   - Cognitive impairment plus infection
   - Rapid physical decline
   - Significant complex symptoms, including pain

8) 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.

9) **If a resident with a neurologic disorder develops any of the 4 things 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.**
SCRIPT 9A

- We want to discuss the fact that because [you] {resident’s name} have/has 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 – which is pneumonia. And that can cause shortness of breath, and make it hard to get enough oxygen to the body.

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

- We have looked for other reasons why this swallowing problem exists, but mainly it is because the NEUROLOGICAL DISORDER has gotten worse.
- And, I’m very sorry to say, but we cannot fix that.
- I am also sorry to let you know that [you] {resident’s name} have/has developed problems indicating a very advanced and final phase of the NEUROLOGICAL DISORDER.
- What are your thoughts about this?

- Allow the resident/SDM to ask any questions that they may have. You might provide examples to justify the impression that 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.

- If [you] {resident’s name} DO/DOES get pneumonia, we can give antibiotics, and they might help control the infection this time around.
- They might help [you] {resident’s name} feel better for a while, but because the NEUROLOGICAL DISORDER is so severe, it is only a matter of time before [you] {she/he} get/gets pneumonia again.
- These setbacks will probably make [you] {resident’s name} weaker and weaker. Eventually [you] {she/he} may die from pneumonia.

- PAUSE. Allow the resident/SDM to ask any questions that they may have.
So, given the situation, we would like to know whether [you] {resident’s name} would wish to get antibiotics if [you] {she/he} get/gets pneumonia. This might give [you] {her/him} 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 at that time, and let nature take its course. If that is what [you] {resident’s name} would wish for, we would do everything to keep [you] {her/him} comfortable and treat any shortness of breath or other distress that happens.

- Allow the resident/SDM 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.

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?

- Clarify for the resident if needed, using the prompts listed above.
- Ask the resident/SDM to verbalize their thoughts. 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.

So, if I understand correctly, if [you] {resident’s name} were to get pneumonia, [your] {her/his} wish at this time would be that we RESTATE YOUR UNDERSTANDING OF THE RESIDENT’S WISHES ABOUT ANTIBIOTICS FOR PNEUMONIA.

- Document this discussion, being as specific as possible.

References
SCRIPT 9B. CARE OF ADVANCING HEART FAILURE

Preliminary Information (script begins on next page):

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

2) There are three ways people in nursing home residents die of heart failure: sudden cardiac death, progressive heart failure, and death related to a different medical condition.

   i. 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.

   ii. Death from progressive heart failure: This involves severe swelling, particularly of the legs and belly, which can be uncomfortable. There can also be fluids build up in the lungs, which leads to serious shortness of breath, anxiety, fear, and discomfort.

   ii. 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) A nursing home 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 that everyone feels comfortable with -- 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 clinic, so it may be important to have providers from this clinic involved in this discussion.

   - The defibrillator can be easily turned off. It is important for the resident/SDM to understand that:
     
     ➢ Deactivating the defibrillator does not involve a surgery or complex intervention.
     
     ➢ Deactivating the defibrillator will not hurt at all: the device remains in place.
     
     ➢ Deactivating the defibrillator does not mean that the resident will die shortly thereafter. The resident may live for a long time and may never experience a cardiac arrest.
     
     ➢ The goal of deactivating the defibrillator is to allow a natural death to occur when the heart beat stops, painlessly and quickly.


   - Also consider developing, with your local arrhythmia clinic, a protocol to facilitate the deactivation of implanted defibrillators for residents who chose to do so.
I would like to talk about [your] {resident’s name} heart. The records mention that [you] {she/he} have/has had 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] {resident’s name} heart condition?

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

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] {resident’s name} here in the nursing home, without the need to be sent to emergency or hospital.

BUT, there may come a time when the heart failure gets so bad that we can no longer make [you] {resident’s name} comfortable here in the nursing home, and at that point there will be an important choice to make.

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 nursing home, where we WILL keep [you] {resident’s name} comfortable, but [you] {she/he} may die sooner.

How do you feel about these choices?

- PAUSE. Open the conversation to the resident and the SDM/family members. Answer all questions they may have.
- It may be appropriate to again discuss the three available philosophies of care (the “big picture”) as in Script 8D (p.23-25).
- Talk about the possibility of going to hospital/emergency 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 nursing home.
- If appropriate, address turning off the defibrillator if the resident have one.

What do you think about this?

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

So, if I understand correctly, if [your] {resident’s name} heart failure were to get worse, [your] {her/his} wish at this time would be that we RESTATE YOUR UNDERSTANDING OF THE RESIDENT’S WISHES ABOUT GOING TO EMERGENCY OR HOSPITAL FOR MORE AGGRESSIVE TREATMENT FOR HEART FAILURE.

- Document this discussion, being as specific as possible.
SCRIPT 9C. USE OF ARTIFICIAL FEEDING TUBES

Preliminary Information (script begins on next page):

1) Meals are more than a way of addressing needs of the body. Meals and meal times 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 makes the person at high risk of choking, or aspirating food or liquids (including saliva), potentially causing pneumonia and other breathing problems.

3) For frail nursing home residents losing the ability to safely swallow food or liquids usually indicates that the final part of life has arrived.

4) When this happens, it is difficult to keep the resident well nourished. There are 4 main choices when this occurs:
   a. A family member or nursing home team member carefully hand feeding the resident by mouth.
   b. 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.
   c. Having a 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.
   d. 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 nursing home 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 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 or not nutrition is provided, the underlying condition that is the cause of the swallowing problem continues to worsen.
We would like to talk to you about problems we have noticed in that {your resident’s name} is having trouble swallowing food and liquids safely, without choking.

Have you noticed this as well? What are your thoughts on this?

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

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. And, we’re sorry to say that we cannot fix that.

We are very sorry to say that this tells us that {your resident’s name} has reached a final phase of life.

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

We will of course continue to help {your resident’s name}. There are a couple of things we could do.

The First Option: We can modify the food by making easier to swallow, and people here in the nursing home can help {your resident’s name} eat more safely.

The Second Option: Some people ask about feeding tubes. There are 2 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, as well as the feeding, 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.

- Allow the resident/SDM 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 these and try to pull them out.

The reason that artificial feedings through tubes does not help people in this situation live longer is probably related to the risks and complications of the tubes and the artificial feedings. 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 advancement of [your] {resident’s name} 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.

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 this, so we can help in making the right decision at the right time in the future?

So if I understand correctly, [your] {resident’s name} current wish would be that we USE/NOT USE a feeding tube.

- Document this discussion, being as specific as possible.

References

SCRIPT 9D. PERMANENT/LONG-TERM USE OF ARTIFICIAL HYDRATION (INTRAVENOUS OR SUBCUTANEOUS FLUIDS)

Preliminary Information (script begins on next page):

Taking in fluids, to keep hydrated, is necessary for life. For nursing home residents, there are temporary and permanent reasons why they may be unable to drink enough fluids to stay hydrated.

a) Temporary Reasons: These are usually acute problems that cause excessive vomiting and/or diarrhea. We are not going to discuss this situation further.

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.

This script below is about Permanent Reasons for dehydration only.

- Swallowing problems make the person at high risk of choking or aspirating food, liquids or saliva, potentially causing pneumonia and other breathing problems.
  - This kind of swallowing difficulty is common in nursing home residents, and happens often with advanced dementia, frailty, Parkinson’s disease, other neurologic disorders, or any advanced disease.
  - For residents who are unable to maintain adequate hydration and nutrition on their own, consult with your dietitian about best practices of modified food and fluid textures. But note that 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.

- Losing interest in drinking (and eating) commonly occurs towards the end of life with advanced dementia, frailty, and other diseases.
  - While this does lead to residents becoming dehydrated, they do not usually suffer from thirst.
  - Research has shown that with advanced dementia, fluids (and food) given artificially do NOT reduce the risk for pneumonia, improve quality of life, function, comfort or prolong survival.

- 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.

- An important thing to recognize is that these situations usually indicate that the final stages of life have begun.

- There are 3 main choices when hydration problems are caused by permanent/long-term reasons:
  a) Resident remains in the nursing home and is encouraged to take in fluids by mouth.
  b) Resident remains in the nursing home and receives artificial fluids through a needle inserted just below the skin into the subcutaneous tissue, known as hypodermoclysis. This option is only available if the nursing home is set up to do it.
  c) Resident is admitted to the hospital and receives fluids intravenously (some nursing homes have this capability within the home too).

- As shown below in this script, for permanent/long-term causes of hydration problems, the focus of discussion is that even after aggressive rehydration (options ‘c’), the problem WILL recur. In other words, that is not a practical, long-term solution. Indeed, the point is that because we cannot fix the cause, there IS NO good long-term solution.
We would like to talk to you about a problem we have noticed. You have/trouble drinking enough liquids, to stay well hydrated.

Have you noticed this as well?

We believe that the reason for this problem with drinking 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/resident’s name are/is still not getting in enough.

It is also important to know that people in this situation do not usually appear to be thirsty, even though they do not drink enough fluids.

I realize this is difficult information to take in. Before going on to talk about options are available, do you have any questions?

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/resident’s name will be given fluids through the vein, but this will stop when you/resident’s name return to the nursing home. Giving fluids through a needle under the skin is something we can do here in the nursing home.

But the problem with this is that after it stops, the problem will return. It does not fix the real problem of being unable to take in enough fluids by mouth.

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

Do you have any questions at this time?

- Make sure that the resident and/or SDM understand how in this situation, giving artificial fluids through a needle should not be done permanently. Ask if they understand all 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 for which of the two main choices is preferred. Document this discussion, being as specific as possible.

>>Script 10E continues on next page<<
- IF the desired choice is CHOICE 1: artificial fluids through a needle (either IV or subcutaneously), then do this part of the script:

🌟 So if I understand correctly, [your] {resident’s name} 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. Because doing this does not fix the cause of the problem, the problem with not being able to drink enough fluids IS going to re-occur. And it’s not possible to continue giving fluids through a needle indefinitely. And doing it over and over again when the problem does re-occur is not practical either.

🌟 SO, we need to come to an agreement on doing this for a limited time only.

🌟 It seems reasonable to give this a try ONCE, and for a limited period of time, say a couple of days. This gives it a chance to get fixed, and to STAY fixed -- but if as expected, it does re-occur, then we will need to be able to accept the reality that this is going to be a permanent problem and to switch over to an approach where providing comfort at the end of life is our goal.

- If this suggestion is not accepted, try to negotiate something reasonable and limited that the resident/SDM can accept.

- Document this discussion, being as specific as possible.
10. INFORMATION TO SUPPORT ACP DISCUSSIONS IN A FEW OTHER COMMON, SPECIFIC CLINICAL SITUATIONS

This section contains information for you (but no Scripts) about other situations that should prove useful in informing ACP discussions with nursing home residents and their SDMs.

10A. CHRONIC OBSTRUCTIVE PULMONARY DISEASE (COPD)

1) In Canadian nursing homes, 8-20% of residents have COPD. COPD is a common cause of death in nursing home residents.

2) COPD is marked by “exacerbations” -- intermittent worsening of breathing. These can be caused by viral or bacterial infection 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 nursing home 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 nursing home 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:
   - The **best predictor** of future hospitalizations and death are the number of prior hospitalizations.
   - Health and function deteriorates faster after a second hospitalization for COPD exacerbation.
   - Mortality rate rises after each COPD exacerbation.

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

6) So, it is important to discuss options for residents with severe COPD. The main options are:
   - Aggressive care, even including transfer to hospital and artificial life support (hopefully which will be only temporary).
   - Aggressive care, even including transfer to hospital but **NOT ALLOWING** use of artificial life support.
   - More conservative care, provided in the nursing home only -- oxygen, medications.
   - 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.
10B. KIDNEY DIALYSIS

1) Patients over the age of 75 years are the fastest growing age group with end-stage renal disease.

2) Among nursing home 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 nursing home 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 nursing home 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 nursing home 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 nursing home residents who are already on dialysis. Residents should be given the chance to consider the likelihood of survival and quality of life, and whether or not 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 nursing home 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. And 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.

10C. DIABETES MANAGEMENT

1) Diabetes mellitus affects 20-30% of nursing home 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) Nursing home 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

<table>
<thead>
<tr>
<th>Status</th>
<th>Functionally independent</th>
<th>Functionally dependent</th>
<th>Frail and/or with dementia</th>
<th>End of life</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical Frailty Index*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>A1C Target</td>
<td>1-3</td>
<td>4-5</td>
<td>6-8</td>
<td>9</td>
</tr>
<tr>
<td>Low-risk hypoglycemia (i.e. therapy does not include insulin or SU)</td>
<td>≤7.0%</td>
<td>&lt;8.0%</td>
<td>&lt;8.5%</td>
<td>A1C measurement not recommended. Avoid symptomatic hyperglycemia or any hypoglycemia.</td>
</tr>
<tr>
<td>A1C Target</td>
<td>7.1–8.0%</td>
<td>7.1–8.5%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Higher-risk hypoglycemia (i.e. therapy includes insulin or SU)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>CBCM Preprandial</td>
<td>4–7 mmol/L</td>
<td>5–8 mmol/L</td>
<td>6–9 mmol/L</td>
<td>Individualized</td>
</tr>
<tr>
<td>Postprandial</td>
<td>5–10 mmol/L</td>
<td>&lt;12 mmol/L</td>
<td>&lt;14 mmol/L</td>
<td></td>
</tr>
</tbody>
</table>

A1C, glycated hemoglobin; CBCM, capillary blood glucose monitoring; SU, sulfonylurea.
* Clinical Frailty Score (1 = very fit to 9 = terminally ill).

Table 2
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;7.5%</td>
<td>Functionally independent: &lt;7.0%</td>
<td>Functionally independent: 7.0%–7.5%</td>
</tr>
<tr>
<td></td>
<td>Complex/Intermediate: &lt;8.0%</td>
<td>Functionally dependent: 7.1–8.0%</td>
<td>Functionally dependent: 7.0%–8.0%</td>
</tr>
<tr>
<td></td>
<td>Very Complex/Poor Health: &lt;8.5%</td>
<td>Frail and/or dementia: 7.1–8.5%</td>
<td>Sub-level frail: &lt;8.5%</td>
</tr>
<tr>
<td></td>
<td></td>
<td>End of life: A1C measurement not recommended. Avoid symptomatic hyperglycemia and any hypoglycemia.</td>
<td>Sub-level dementia: &lt;8.5%</td>
</tr>
</tbody>
</table>

End of life: avoid symptomatic hyperglycemia
10D. STOPPING MEDICATIONS (DEPRESCRIBING)

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

2) But 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 just the duration of life.

3) In all people, regardless of age and situation, 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, nursing home 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 in the care of frail, elderly people 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 nursing home residents with end-stage diseases and a limited life expectancy, the chance of benefit from continuing statins is little to none.

   ➢ Also, 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
11. 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. 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.

11A. Survival After Cardiac Arrest in Nursing Homes

Start (100 alive)                    1 Month Later (3 alive)

11B. Survival With Severe Frailty in Nursing Homes

Start (100 alive)                      3 Months Later (15 alive)

(adapted from Luo et al., *JAMDA*, 2015)
11C. Survival For CHESS Score of 3 in Nursing Homes

Start (100 alive)                      6 Months Later (42 alive)

(adapted from Hirdes et al., *PLoS ONE*, 2015)
11D. Survival For CHESS Score of 4 in Nursing Homes

Start (100 alive)                      6 Months Later (28 alive)

(adapted from Hirdes et al., *PLoS ONE*, 2015)
11E. Survival For CHESS Score of 5 in Nursing Homes

Start (100 alive)                       6 Months Later (8 alive)

(adapted from Hirdes et al., *PLoS ONE*, 2015)
11F. Survival With Congestive Heart Failure (CHF) in Nursing Homes

Start (100 alive)                      6 Months Later (69 alive)

(adapted from Foebel et al., J Card Fail, 2013)
Advance Care Planning (ACP): 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.

Substitute Decision Makers (SDMs): the person or persons who will make treatment and personal care decisions if the resident loses the capacity to make these decisions in the future. When SDMs make decisions, they must do so as the resident would have done IF the resident were able to make the decision herself/himself. SDMs must consider:

1. Prior wishes expressed by the resident that apply to the current situation and are possible to follow.
2. The best interests of the resident -- if the resident did not express wishes.

Qualities of an SDM

• Willing to understand, honor and follow the resident’s wishes, values and beliefs as much as possible when the resident can no longer make his/her own decisions.
• Able to ask questions and advocate for the resident with the health care team.
• Able to make difficult decisions on behalf of the resident.

ACP Discussions: 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 resident’s disease, as well as the potential outcomes of the treatment options that are available.

A series of BABEL ACP discussions will take place with residents and SDMs when they move into the nursing home, when the resident’s situation changes, and on a yearly basis. Additional ACP discussions can take place anytime.

The goal of ACP discussions is to identify and document a resident’s values and preferences for care, to ensure his/her wishes are followed across healthcare settings.
Steps in Advance Care Planning
1. Inform residents and family members about the resident’s medical conditions, likely clinical course of those conditions, and most likely outcomes for common medical treatments toward the end of life.
2. Residents are given the opportunity to express their wishes.
3. Document, communicate and honor those wishes to provide care and medical treatments consistent with the resident’s wishes.

What should be covered in the discussion?
• ACP discussions with the resident and SDM(s) include the following:
  o The values, goals and fears of the resident
  o Detailed conversations about preferences of medical treatments
• When discussing medical treatments, explain:
  o The condition of the resident
  o Options for care -- including both aggressive approaches and comfort care
  o Potential benefits and potential risks of the options

Outcomes of ACP discussions
• The resident makes the decision on whom their SDM(s) will be.
• The resident shares wishes, values and beliefs about healthcare with their SDM(s) and health care providers.
• ACP discussions can help prepare residents, SDMs and nursing home staff for decision-making conversations in the future.
• ACP discussions are not primarily about making medical decisions or obtaining consent.

Why should staff encourage ACP discussions?
Residents should be encouraged to engage in ACP discussions, because they:
• Respect a resident’s right to self-determination at the end-of-life.
• Improve resident/family members’ satisfaction with end-of-life care.
• Decrease the level of distress experienced by family.
• Decrease unwanted medical tests and treatments ICU if this is not the resident’s wish.

How often should ACP discussions take place?
• ACP is an ongoing process of reflection that should be revisited with major changes in health or when the resident’s wishes, values or beliefs change.
• Revisions/updates must be communicated to the resident’s SDM(s).
• All ACP discussions should be documented and dated and should contain the most up to date information.

Documentation is key to ensure that the resident’s wishes are transferred with them and known across healthcare settings.
**TIPS: HOW TO START THE DISCUSSION**

Ask the resident:

*What do you understand about your illness or what’s happening to you?*

- Then offer to provide information about prognosis, etc. Check who they may want present for this discussion.

You are well now, but it is good to plan for the future. *Do you have an advance care plan? Do you know what I mean by this?*

- If yes, discuss details. If no, then ask, *If we need to make decisions about your care and you were unable to speak for yourself, whom would you want us to speak to about your care?*

*What if you suddenly became ill or had an accident – and couldn’t speak for yourself? Have you talked to your substitute decision maker (or anyone else) about your wishes or preferences for health care that may come up (e.g., resuscitation)? May I ask what you discussed?*

- Explore discussions with family, SDM, health care providers.

*What do we need to know about you as a person, in order to provide you with the best possible care?*

*Do you have the information you need to make decisions about the kinds of medical treatments you want or do not want, if you become very sick with a life-threatening illness?*

**Ask yourself:**

*Did I ask the resident about preferences for end-of-life care?*

*Did I know whom to contact if the resident cannot communicate their wishes?*

*Did I include the family?*

*Do I feel confident that I know the resident’s wishes for care?*

*Did I accurately document the nature of the discussion and the resident’s wishes?*

**Need more information?**

**Video Resource**

For more information on how to begin the discussion with your residents, please refer to the following video, *Talking about residents’ goals with them:*

- [https://www.youtube.com/watch?v=FzxFnEpsxr0](https://www.youtube.com/watch?v=FzxFnEpsxr0)

**Written Resources (online)**

1. **SpeakUp:** Start the conversation about end-of-life care. Available from:
   - [Ontario version](https://www.speakupontario.ca/resource/acp-workbook-en/)

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13. BABEL Advance Care Planning (ACP):
Pre-Discussion Guide for Physicians & Nurse Practitioners
Better tArgeting, Better outcomes for frail ELderly patients

IS THIS RESIDENT AT HIGH RISK OF A MEDICAL EMERGENCY OR DEATH?
The following, all available from the MDS (Minimum Data Set collected in many nursing homes in Canada and elsewhere) indicate a high risk of dying in the next 6-12 months: (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 nursing homes in most of Canada (including your province), it culminates in a score that ranges 0–5. Here is the relationship between CHESS score and survival among Nursing Home residents in Canada:

WHAT ARE THE OBJECTIVES OF THE DISCUSSION?
To help your resident and her/his Substitute Decision Makers (SDMs):
1. Prepare for medical emergencies
2. Understand the medical situation and prognosis
3. Discuss his/her 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?
The assessment of your resident’s capacity to make their own decisions is built into the script-guided discussions of BABEL ACP. [reference: Stuart et al. J. Am. Med. Dir. Assoc., 19(2):106-109, 2017]

ARE THERE ANY RESIDENT HANDOUTS FOR THE DISCUSSION?
We have created & collected excellent written and online materials about ACP planning. These include:
- A trifold pamphlet called Advance Care Planning: Getting What You Want From the Care We Provide. It briefly informs about the key aspects of advance care planning.
- A pamphlet called SpeakUp, created by a consortium of Canadian organizations.
The BABLE WORKBOOK -- this is a how-to guide for conducting ACP Discussions in the Intervention nursing homes -- there are diagrams in Section 10 (pages 46-50) of the workbook that may help residents and SDMs to understand the prognostic implications of certain high-risk characteristics.

**WHAT IS THE PLAN OF ACTION FOR THIS ACP DISCUSSION**

**Quick Team Huddle** (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
- Explain SDM responsibilities and roles
- Prepare the SDM for emergencies

**Physician or NP led (if present)**

**Clinical Situation**
- 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’s specific medical context, discuss the full range of possible medical interventions, both inside and outside the nursing home.

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CHECKLIST FOR THE FULL BABEL ACP DISCUSSION

1. Resident name: _________________________________________________

2. Date of this discussion: ___________ 3. Date of Checklist completion: ___________

4. Name of staff discussion leader: ___________________________________

5. Check ALL that participated (either in person, phone, Skype, or any other way in “real time”):

☐ Resident ☐ Main substitute decision-maker ☐ Nurse(s) ☐ Social Worker
☐Physician ☐ Nurse practitioner ☐ Spiritual Advisor ☐ Director of Care ☐ Other(s)

• Before this Discussion, you should review Sections 3, 4, and 7 of the BABEL Workbook.

<table>
<thead>
<tr>
<th>ITEM</th>
<th>Check when completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attempt to talk to the resident’s family physician by phone -- p.15</td>
<td>☐</td>
</tr>
<tr>
<td>Identify emergencies this resident is most likely to experience -- p.16-17</td>
<td>☐</td>
</tr>
<tr>
<td>Have the 5 minute huddle prior to the discussion -- p.18</td>
<td>☐</td>
</tr>
<tr>
<td>Clarify the Role of the SDM -- Script A (section 8A; p.19-20)</td>
<td>☐</td>
</tr>
<tr>
<td>Prepare SDM for Emergencies -- Script B (section 8B; p.21)</td>
<td>☐</td>
</tr>
<tr>
<td>Review clinical situation and prognosis -- Script C (section 8C; p.22)</td>
<td>☐</td>
</tr>
<tr>
<td>Explain philosophies of care -- Script D (section 8D; p.23-25)</td>
<td>☐</td>
</tr>
<tr>
<td>Address full range of medical options -- Script E (section 8E; p.26-27)</td>
<td>☐</td>
</tr>
<tr>
<td>Conclude this discussion -- Script F (section 8F; p.28)</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 her/his own medical decisions, to Severely impaired ability to make her/his own medical decisions:

<table>
<thead>
<tr>
<th>Fully independent 1</th>
<th>Somewhat independent 2</th>
<th>Moderately impaired 3</th>
<th>Severely impaired 4</th>
<th>Unclear or unknown</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

• Finally, 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 emergency</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>

Place this document in the resident’s chart, or an equivalent notation of the checklist of treatment options located at the bottom of this page.