

## LIFECOURSE – VISIT FRAMEWORK

This visual of the semi-structured visit framework offers a more in depth view of how the LifeCourse approach operationalizes the domains of palliative care in the context of the visit. Beginning with what matters most and goals allows the care guide to keep these factors in mind as they move further into the discussion.

There are specific questions and assessments that care guides use to explore the palliative care domains. Assessments include standard measures such as the ESAS, PPS and FICA. Both the question sets and the assessments can open the door to conversations and can also trigger follow up with a patient's provider.

After the sixth visit the use of question sets become more individualized, whereas the uses of assessment tools are regularly scheduled.

The care guide is trained to listen, observe and recognize information and changes in the patients' condition. They then empower patients and families to optimize their existing social support network, link to system resources and care team members and follow up with their provider.

		Visit #1	Visit #2	Visit #3	Visit #4	Visit #5	Visit #6	Ongoing
<b>Domain Question Sets</b>	Physical	■						■
	Family/Caregiver	■						■
	Psychological		■			■		■
	Cultural		■	■				■
	Ethical		■	■				■
	Social			■		■		■
	Financial/Legal			■		■		■
	Spiritual				■			■
	Legacy & Bereavement					■		■
	End of Life						■	■
<b>Assessment Tools</b>	FACIT-Pal	■					■	■
	ESAS	■			■			■
	PPS	■	■	■	■	■	■	■
<b>ACP</b>	■	■	■	■	■	■	■	

## LIFECOURSE – CORE QUESTIONS AND ASSESSMENTS

LifeCourse recommends that questions and assessments occur during the visit indicated. However, care guides should use their own judgment to determine whether or not this order is appropriate for all patients. All questions and assessments should be completed by the end of Visit 6.

VISIT 1	
Topic	Questions and Assessment Tools
Assessment	Patient-reported Health Outcomes Measurement Information System (FACIT-Pal Quality of Life Survey – patient self-assessment)
Getting to Know You	<ul style="list-style-type: none"> <li>▪ Tell me a little about yourself. What interests you about LifeCourse?</li> <li>▪ What would you like your healthcare team to know about you?</li> </ul>
Physical: Medical Condition	<ul style="list-style-type: none"> <li>▪ What do you understand about your current condition?</li> <li>▪ Given your current understanding of your illness, what does the future look like for you?</li> <li>▪ What symptoms do you experience or are most bothersome?</li> <li>▪ Do your symptoms seem manageable? How are they affecting your daily life?</li> <li>▪ How would you describe your current care plan?</li> </ul>
Physical: Life Changes	<ul style="list-style-type: none"> <li>▪ How has living with [your illness] changed your life?</li> <li>▪ Are you able to live independently or do you need help from others?</li> </ul>
Assessments	Edmonton Symptom Assessment System (ESAS – patient self-assessment) Palliative Performance Scale (PPS – observational assessment)
Family: Support System	<ul style="list-style-type: none"> <li>▪ Who is involved in your care and support? (<i>names and relationship to patient</i>)?</li> <li>▪ Who would you like us to include as the main person for communication?</li> <li>▪ How do your family and friends support you?</li> <li>▪ In what areas (if any) do you need additional support?</li> <li>▪ What strengths do your family and friends have?</li> <li>▪ What challenges are your family and friends facing (if any)?</li> </ul>
What Matters Most and Goals	<ul style="list-style-type: none"> <li>▪ What matters most to you? What is most important to you?</li> <li>▪ What are you focused on?</li> </ul>
VISIT 2	
Topic	Questions and Assessment Tools
Setting Intention	<ul style="list-style-type: none"> <li>▪ What is new or has changed since we last met?</li> <li>▪ Is there anything you would like to cover in our visit today?</li> </ul>

What Matters Most and Goals	<ul style="list-style-type: none"> <li>▪ You said what matters most to you is _____. Is this still true for you?</li> <li>▪ Are we working together on what matters most to you? Is there anything new to add?</li> <li>▪ You said you are focused on _____. Is this still true for you? Has anything changed? Is there anything new to add?</li> </ul>
Assessment	Palliative Performance Scale (PPS – observational assessment)
Psychological: Mental Health and Grief	<ul style="list-style-type: none"> <li>▪ How would you describe your overall mental health and wellbeing?</li> <li>▪ Do you have any worries about your mental health or wellbeing?</li> <li>▪ Have you experienced feelings of grief over recent or past changes or losses?</li> </ul>
Ethical: Advance Care Plan	<p><i>For patients with existing ACP documents in their medical record:</i></p> <ul style="list-style-type: none"> <li>▪ Are these ACP documents from your medical record the current documents for you?</li> <li>▪ Have there been any changes in these documents or in your health care agent?</li> <li>▪ Have you discussed your ACP documents with your healthcare agent (s)? Does your agent(s) have copies?</li> </ul> <p><i>For patients without ACP documents in their record:</i></p> <ul style="list-style-type: none"> <li>▪ Have you completed an advance care plan? <ul style="list-style-type: none"> <li>○ If yes, do you have a copy? Would you like it scanned into your record?</li> <li>○ If no, can I schedule an advance care planning session with you and your health care agent?</li> </ul> </li> </ul>
<b>VISIT 3</b>	
<b>Topic</b>	<b>Questions and Assessment Tools</b>
Setting Intention	<ul style="list-style-type: none"> <li>▪ What is new or has changed since we last met?</li> <li>▪ Is there anything you would like to cover in our visit today?</li> </ul>
What Matters Most and Goals	<ul style="list-style-type: none"> <li>▪ You said what matters most to you is _____. Is this still true for you?</li> <li>▪ Are we working together on what matters most to you? Is there anything new to add?</li> <li>▪ You said you are focused on _____. Is this still true for you? Has anything changed? Is there anything new to add?</li> </ul>
Assessments	<p>Who's at Your Table Activity (patient and care guide discussion tool)</p> <p>ACP: Validation, Reconciliation, and Clarification (as appropriate)</p> <p>Palliative Performance Scale (PPS – observational assessment)</p>
Social: Support System Challenges	<ul style="list-style-type: none"> <li>▪ How would you describe your support system?</li> <li>▪ What is most challenging for you now?</li> </ul>

	<ul style="list-style-type: none"> <li>How have you managed to overcome the challenges that you have faced?</li> <li>Who or what helps you through difficult times?</li> </ul>
Cultural: Decision Making	<ul style="list-style-type: none"> <li>How you prefer to make decisions?</li> <li>Do you want serious health information shared with you?</li> <li>Do you prefer serious health conversations to be simple, detailed, softened, direct, or something else?</li> <li>Is there anyone else you want serious health information shared with?</li> </ul>
Ethical: Decision Making Capacity	<ul style="list-style-type: none"> <li>During the past 12 months, have you experienced confusion or memory loss that is happening more often or is getting worse?</li> </ul>
<b>VISIT 4</b>	
<b>Topic</b>	<b>Questions and Assessment Tools</b>
Setting Intention	<ul style="list-style-type: none"> <li>What is new or has changed since we last met?</li> <li>Is there anything you would like to cover in our visit today?</li> </ul>
What Matters Most and Goals	<ul style="list-style-type: none"> <li>You said what matters most to you is _____. Is this still true for you?</li> <li>Are we working together on what matters most to you? Is there anything new to add?</li> <li>You said you are focused on _____. Is this still true for you? Has anything changed? Is there anything new to add?</li> </ul>
Assessment	<p>Edmonton Symptom Assessment System (ESAS – patient self-assessment)</p> <p>ACP: Validation, Reconciliation, and Clarification (as appropriate)</p> <p>Palliative Performance Scale (PPS – observational assessment)</p>
Spiritual: FICA	<p><u>F: Faith, Belief, Meaning</u></p> <ul style="list-style-type: none"> <li>Do you consider yourself spiritual or religious? Do you have spiritual (or other) beliefs that help you cope with stressful or difficult times?</li> <li>What gives your life meaning? Do you have a religious or spiritual affiliation?</li> </ul> <p><u>I: Importance/Influence</u></p> <ul style="list-style-type: none"> <li>What importance does your spirituality have in your life?</li> <li>Has spirituality influenced how you take care of yourself, your health?</li> <li>Does your spirituality influence you in your healthcare decision making?</li> </ul> <p><u>C: Community</u></p> <ul style="list-style-type: none"> <li>Are you part of a spiritual or religious community? How is this of support to you?</li> <li>Is there a group or community of people you really love or who are important to you?</li> </ul> <p><u>A: Address/Action in Care</u></p> <ul style="list-style-type: none"> <li>How would you like your care team to address these issues in your care?</li> </ul>

VISIT 5	
Topic	Questions and Assessment Tools
Setting Intention	<ul style="list-style-type: none"> <li>▪ What is new or has changed since we last met?</li> <li>▪ Is there anything you would like to cover in our visit today?</li> </ul>
What Matters Most and Goals	<ul style="list-style-type: none"> <li>▪ You said what matters most to you is _____. Is this still true for you?</li> <li>▪ Are we working together on what matters most to you? Is there anything new to add?</li> <li>▪ You said you are focused on _____. Is this still true for you? Has anything changed? Is there anything new to add?</li> </ul>
Assessment	ACP: Validation, Reconciliation, and Clarification (as appropriate) Palliative Performance Scale (PPS – observational assessment)
Financial/Legal	<ul style="list-style-type: none"> <li>▪ Do you have a plan for taking care of things such as household bills if you were away from home?</li> <li>▪ Have you determined if you need a legal will?</li> </ul>
Legacy	<ul style="list-style-type: none"> <li>▪ How would you like to share your memories with family and friends?</li> </ul>
VISIT 6	
Topic	Questions and Assessment Tools
Setting Intention	<ul style="list-style-type: none"> <li>▪ What is new or has changed since we last met?</li> <li>▪ Is there anything you would like to cover in our visit today?</li> </ul>
What Matters Most and Goals	<ul style="list-style-type: none"> <li>▪ You said what matters most to you is _____. Is this still true for you?</li> <li>▪ Are we working together on what matters most to you? Is there anything new to add?</li> <li>▪ You said you are focused on _____. Is this still true for you? Has anything changed? Is there anything new to add?</li> </ul>
Assessments	ACP: Validation, Reconciliation, and Clarification (as appropriate) Palliative Performance Scale (PPS – observational assessment)
Physical: Medical Condition (repeat from Visit #1)	<ul style="list-style-type: none"> <li>▪ What do you understand about your current condition?</li> <li>▪ Given your current understanding of your illness, what does the future look like for you?</li> <li>▪ What symptoms do you experience or are most bothersome?</li> <li>▪ Do your symptoms seem manageable? How are they affecting your daily life?</li> <li>▪ How would you describe your current care plan?</li> </ul>

Physical: Life Changes (repeat from Visit #1)	<ul style="list-style-type: none"> <li>How has living with [your illness] changed your life?</li> <li>Are you able to live independently or do you need help from others?</li> </ul>
Care at the End of Life	<ul style="list-style-type: none"> <li>What would you hope for if you had a complication, or if your illness was worsening?</li> <li>What experiences have you had with family or friends who have died or are living with serious illness? If you were in a similar situation, what would you want or not want?</li> <li>What fears or worries do you have about future medical care?</li> <li>If you were at the end of your life, what would bring you comfort or support?</li> <li>What have you heard about palliative care/hospice? Would you like to learn more?</li> </ul>

ONGOING	
Topic	Questions and Assessment Tools
Setting Intentions	<ul style="list-style-type: none"> <li>What is new or has changed since we last met?</li> <li>Is there anything you would like to cover in our visit today?</li> </ul>
What Matters Most and Goals	<ul style="list-style-type: none"> <li>You said what matters most to you is _____. Is this still true for you?</li> <li>Are we working together on what matters most to you? Is there anything new to add?</li> <li>You said you are focused on _____. Is this still true for you? Has anything changed? Is there anything new to add?</li> </ul>
Assessment	ACP: Validation, Reconciliation, and Clarification (as appropriate)
<i>Every month</i>	Palliative Performance Scale (PPS – observational assessment)
<i>Every 3 months</i>	Edmonton Symptom Assessment System (ESAS – patient self-assessment)
<i>Every 6 months</i>	FACIT-Pal (Quality of Life Survey – patient self-assessment)
Revisit question sets ( <i>as needed</i> )	

TIME OF DEATH	
Bereavement	See Bereavement Domain Summary