

Communicating Relapse & Involving Families


A STRUCTURED APPROACH FOR R/R CLL

Communicating Relapse & Involving Families

These conversations are never easy — but a clear structure can help you stay present, focused, and patient-oriented. Use this guide to navigate the conversation step by step.

01 Step


Setting the moment
Create the conditions for the conversation



OPEN STEP → TO DO

02 Step


Understanding the patient
Ground in their previous experience and context



OPEN STEP → TO DO

03 Step


Naming relapse clearly
Deliver the information in a way they can take in



OPEN STEP → TO DO

04 Step


Responding to their reaction
Recognise the response and support before moving forward



OPEN STEP → TO DO

05 Step


Orienting to next steps
Restore direction and clarity without overwhelm



OPEN STEP → TO DO

06 Step

Managing who is in the room
Involve families while keeping the patient central



OPEN STEP → TO DO

KEY PRINCIPLE

You do not need to finish all steps in one consultation.

- IN R/R CLL, REMEMBER**
- ✓ Shaped by previous experiences
 - ✓ Patients may react differently than at first diagnosis
 - ✓ Family may already be involved — but not always aligned

- COMMON PITFALLS**
- ✗ Moving too quickly from relapse to options
 - ✗ Over-explaining before the information has landed
 - ✗ Ignoring previous treatment experience
 - ✗ Letting others speak for the patient

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STEP 01 OF 06

01 Setting the moment

Create the conditions for the conversation before you share the information.

WHY THIS MATTERS IN R/R CLL
 This is not the first time — but it still carries weight. Previous experiences may be activated quickly. The way you start signals that this deserves attention.

MARK STEP COMPLETE

WHAT TO ACTIVELY DO

1 Create availability

- Minimise interruptions
- Ensure you will not be called away
- Silence or step away from your phone

SIGNALS I am here for this conversation.

2 Create physical presence

- Sit down
- Be at eye level
- Avoid speaking while moving or standing

SIGNALS This is not a quick update.

3 Reduce background noise

- Close the door or curtain if possible
- Turn off TV / distractions

SIGNALS This space is contained.

4 Position the moment

- Do not start abruptly
- Mark the transition into the conversation

SIGNALS The setting communicates importance before the words land.

HOW TO — EXAMPLES

“Let's take a moment to go through your results together.”

“We have the results back, and I'd like us to discuss them.”

WHAT NOT TO DO

- ✗ Start while standing, checking notes, or moving
- ✗ Let interruptions happen without containment
- ✗ Say “I'll be quick”
- ✗ Move directly into results

Before the words land, the setting already communicates their importance.

Communicating Relapse & Involving Families



STEP 02 OF 06

02 Understanding where the patient is coming from

Ground the conversation in the patient's previous experience, expectations, and current position.

WHY THIS MATTERS IN R/R CLL
 This is not a first encounter with uncertainty. Patients may anticipate relapse, be surprised despite monitoring, or carry emotional residue from prior treatments. The same information can land very differently depending on what they've been through and what they expect now.

MARK STEP COMPLETE

WHAT TO ACTIVELY DO

1 Previous experience

- What has the patient already been through?
- How did they experience prior treatment?

SIGNALS Emotional context they carry into this conversation.

2 Current understanding

- What do they think is happening?
- What have they been told so far?

SIGNALS Reveals the starting point and the gap from reality.

3 Expectations & concerns

- Are they anticipating progression?
- Are they worried — or assuming stability?

SIGNALS Anticipate reaction and adjust how you deliver news.

HOW TO — EXAMPLES

“What's your sense of how things have been going recently?”

“What have you been told so far about the results?”

WHAT NOT TO DO

- Assume the patient already knows
- Skip directly to results
- Correct or challenge prematurely
- Turn this into a long discussion

Before sharing new information, understand what the patient is already holding.

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STEP 03 OF 06

03 Naming relapse and sharing information clearly

Deliver the information clearly, in a way the patient can take in.

WHY THIS MATTERS IN R/R CLL
 How you deliver information shapes how it is understood. Clarity, pacing and the patient's language reduce confusion and help them stay with you.

MARK STEP COMPLETE

WHAT TO ACTIVELY DO

<p><input type="checkbox"/> 1 Signal what is coming</p> <ul style="list-style-type: none"> • Prepare the patient • Mark the transition into the news <hr/> <p>SIGNALS A brief signal lets them brace and listen.</p>	<p><input type="checkbox"/> 2 State it clearly</p> <ul style="list-style-type: none"> • Use direct, simple language • "The results showed... which means..." <hr/> <p>SIGNALS "The CLL is not responding to this treatment. (pause)"</p>
<p><input type="checkbox"/> 3 Give it in small chunks</p> <ul style="list-style-type: none"> • One idea at a time, then pause • Check understanding lightly <hr/> <p>SIGNALS "Does that make sense so far?"</p>	<p><input type="checkbox"/> 4 Adjust your pace</p> <ul style="list-style-type: none"> • If the patient follows → continue • If not → slow down or repeat <hr/> <p>SIGNALS Clarity, in small steps, at the patient's pace.</p>

HOW TO - EXAMPLES

"I'm afraid the results are not what we were hoping for."

"We need to talk about what the results are showing."

WHAT NOT TO DO

- ✗ Deliver everything at once
- ✗ Use long explanations or jargon
- ✗ Overload with options
- ✗ Rush to reassurance

Clarity, in small steps, at the patient's pace.

Communicating Relapse & Involving Families



STEP 04 OF 06

04 Responding to the patient's reaction

Recognise the patient's response and respond in a way that supports them before moving forward.

WHY THIS MATTERS IN R/R CLL
How you respond helps the patient feel understood and stay engaged in the conversation.

MARK STEP COMPLETE

WHAT TO ACTIVELY DO

1 Notice the response

- Emotion: distress, silence, flatness
- Engagement: questions, withdrawal
- Body: posture, breathing

SIGNALS What do you see right now?

2 Respond with empathy

- Name what you see, gently
- Validate — normalise the reaction

SIGNALS "It's understandable to feel this way."

3 Allow space

- Silence is part of the conversation
- Give time for processing
- Do not rush to reassure

SIGNALS Holding the moment is part of the response.

HOW TO — EXAMPLES

"I can see this is difficult to hear."

"This is a lot to take in."

"That's not what you wanted to hear, I know."

WHAT NOT TO DO

- ✗ Ignore emotion or bypass it
- ✗ Move too quickly forward
- ✗ Over-reassure ("we have options")
- ✗ Force the patient to talk
- ✗ Minimise or dismiss feelings

↳ If they cannot engage → [Toolkit 5 \(Readiness\)](#). If they need support → [Toolkit 4 \(Support\)](#).

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STEP 05 OF 06

05 Orienting to next steps

Help the patient understand what happens next without overwhelming them.



WHY THIS MATTERS IN R/R CLL

After hearing of relapse, patients may feel disoriented, may jump ahead, or may not be ready to decide. The goal is to restore direction and clarity in order to move towards decision.

MARK STEP COMPLETE

WHAT TO ACTIVELY DO

1 Anchor the next step

- Give direction
- Make it about process, not decision

SIGNALS Restore a sense of order.

2 Sequence the process

- "First we'll go through the options"
- "Then we'll decide together what fits best"

SIGNALS Reassure through structure.

3 Contain the scope

- Avoid opening multiple pathways
- Stay focused on what happens next

SIGNALS "Let's focus on this for now, not everything ahead."

4 Reassure through structure

- Not through optimism
- Use steady, predictable wording

SIGNALS "Step by step until we make a decision."

HOW TO – EXAMPLES

"The next step is for us to look at the treatment options together."

"We don't need to decide today — we'll go through this step by step."

WHAT NOT TO DO

- ✗ Move straight into full decision-making
- ✗ Present all treatment options at once
- ✗ Overload with details
- ✗ Try to solve everything in one conversation

↳ If not ready to decide → [Toolkit 5 \(Readiness\)](#). If they need support processing → [Toolkit 4 \(Support\)](#).

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STEP 06 OF 06

06 Managing who is in the room — involving families

Understand and manage how family or caregivers influence the conversation — while keeping the patient central.

WHY THIS MATTERS IN R/R CLL
 Family members are often already involved and emotionally invested, carrying their own expectations. In relapse, dynamics may intensify, roles may shift and tensions may surface. The patient remains the primary focus of the conversation.

MARK STEP COMPLETE

WHAT TO ACTIVELY DO

1 Acknowledge who is present

- Briefly recognise others in the room
- Clarify presence without formal interrogation

SIGNALS “It’s good that you’re here together.”

2 Keep the patient at the centre

- Address the patient first
- Maintain eye contact primarily with them

SIGNALS The patient remains the primary focus.

3 Observe how roles emerge

- Who speaks first?
- Who answers for the patient?
- Who stays silent?

SIGNALS Notice patterns before responding.

4 Gently regulate the interaction

- If someone dominates: “Let me hear from you first.”
- If patient defers: invite their perspective.

SIGNALS Maintain a shared but patient-led conversation.

HOW TO — EXAMPLES

- “It’s good that you’re here together.”
- “Let me just hear from you first.”
- “I’d like to understand how this feels from your perspective.”

WHAT NOT TO DO

- Let family speak instead of the patient
- Ignore family dynamics
- Take sides
- Shift focus away from the patient

Include others — but always return to the patient's experience and decision space.