A PRACTICAL FRAMEWORK · ASK — LISTEN — OFFER

Shared Decision-Making in R/R CLL

By the time a patient sits across from you with relapsed or refractory CLL, the conversation has changed. They arrive with lived experience and hard-won insight about what they can and cannot endure — clinically relevant data. SDM recognises that the best plan emerges when clinical expertise meets patient expertise.

A METHOD OF CARE

SDM is not merely a technique applied during a consultation — it is a method of care that shapes the entire clinical relationship.

Ask

2–3 MIN

Invite the patient in & explore what they bring

Signal that this will be a two-way conversation; surface what the patient already knows, feels, and has endured.

OPEN STEP →

Listen

3–5 MIN

Understand values, preferences & what matters now

Uncover what truly drives this patient's decision — not what you assume drives it.

OPEN STEP →

Offer

3–5 MIN

Recommend, decide together & plan follow-up

Translate clinical evidence through the lens of the patient's stated values; co-create a plan that fits their life; establish follow-up.

OPEN STEP →

FOUR WAYS PATIENTS & CLINICIANS COLLABORATE

RECOGNISE THE MODE — AND THE MODE THE PATIENT NEEDS

Weighing alternatives

Comparing defined options against the patient's priorities to find the best match.

R/R CLL
Balancing efficacy, side-effect profile, and dosing convenience.

Reconciling conflicts

Navigating tension between what the patient wants and what is feasible — or between competing goals.

R/R CLL
Patient wants aggressive treatment but family urges comfort care; or prioritises both longevity and avoiding hospital visits.

Problem-solving

Working together to overcome practical barriers to an otherwise agreed plan.

R/R CLL
Accepts a regimen needing frequent monitoring but lives 3 hours away — finding workable logistics.

Making meaning

Helping the patient process what the disease trajectory means for identity, relationships, and future.

R/R CLL
Facing third-line therapy, the patient asks: "At what point do we stop?"

STEP 1 OF 3 · ASK · TYPICAL 2–3 MIN

Invite the patient in & explore what they bring

GOAL

Signal that this will be a two-way conversation; surface what the patient already knows, feels, and has endured.

WHAT THIS SOUNDS LIKE

OPENING THE DOOR

> *"I know today's results are not what either of us hoped for. I want us to think through the next steps together."*

> *"There are several directions we could take from here, and I'd like your input on what feels right for you."*

> *"I'll walk you through the main paths, then we can look at each one more closely."*

MAPPING PRIOR EXPERIENCE

> *"Before I go into details, what have you heard about the treatments available at this stage?"*

> *"Looking back at your last treatment, what was the most difficult part for you?"*

> *"Can you tell me what you understand about these options? I want to make sure I explained everything clearly."*

WHEN THEY ASK YOU TO DECIDE

> *"I have a clinical perspective I'm glad to share. But first, I'd like to hear what matters most to you, so my advice can really match your needs."*

IDENTIFY THE COLLABORATIVE MODE

Listen for the kind of collaborative work the patient needs — and let your next moves match their mode.

1. **Weighing alternatives**
   Comparing defined options against the patient's priorities.
2. **Reconciling conflicts**
   Tension between what they want and what is feasible.
3. **Problem-solving**
   Overcoming practical barriers to an agreed plan.
4. **Making meaning**
   What the disease trajectory means for their life.

STEP 2 OF 3 · LISTEN · TYPICAL 3–5 MIN

Understand values, preferences & what matters now

GOAL

Uncover what truly drives this patient's decision — not what you assume drives it.

WHAT THIS SOUNDS LIKE

SURFACING VALUES & PREFERENCES

> *"As you think about what comes next, what matters most to you right now?"*

> *"Has anything changed in your life since our last conversation that might shape how you want to approach this?"*

> *"Is there someone else who should be part of this conversation — a partner, a family member, someone you lean on?"*

EXPLORING CONCERNS

> *"Of everything you went through with the last treatment, what's the one thing you'd most want to avoid this time?"*

> *"Are there practical difficulties — travel, work, caregiving — that would make certain schedules difficult?"*

> *"What's your biggest worry about starting something new right now?"*

LISTENING TECHNIQUES

1. **Resist filling silence**
   After a question, wait. Five seconds of quiet often unlocks what a follow-up cannot.

2. **Reflect back what you hear**
   "So staying independent enough to care for your husband matters more than how long the remission lasts."

3. **Name the weight of the moment**
   "I can see this decision feels heavier after what you've been through."

4. **Verify comprehension gently**
   "In your own words, how would you describe the choice we're looking at?"

STEP 3 OF 3 · OFFER · TYPICAL 3–5 MIN

Recommend, decide together & plan follow-up

GOAL

Translate clinical evidence through the lens of the patient's stated values; co-create a plan that fits their life; establish follow-up.

WHAT THIS SOUNDS LIKE

PRESENTING OPTIONS

> *"Based on what you've told me and your treatment history, here are the options I think we should focus on."*

> *"Let me compare these two options side by side, focusing on the things that worry you."*

REACHING A DECISION

> *"It's completely fine to take more time. Would you like to think about this, or are you ready to decide today?"*

> *"Based on everything we've discussed, which option feels right to you?"*

PLANNING FOLLOW-UP

> *"Let's check in at [timeframe] to see how this is working for you."*

> *"If at any point you feel this plan isn't working, please contact us so we can adjust the approach."*

COMMUNICATING NUMBERS WITHOUT LOSING THE PATIENT

1. **Anchor in natural frequencies**
   "Out of 100 patients in your situation, roughly 70 see their disease respond."

2. **Hold the denominator constant**
   Compare options on the same scale — don't switch between them.

3. **Drop the relative risk**
   Avoid "50% better" — say "30 out of 100 vs. 20 out of 100."

4. **Frame both ways**
   "88 out of 100 will not have this side effect; 12 out of 100 will."

WHAT CHANGES AFTER RELAPSE

What makes this conversation different

The relapse setting introduces dynamics rarely present at diagnosis. Understanding these shifts helps you calibrate the conversation.

WHAT THE PATIENT MAY BE EXPERIENCING	HOW THIS SHOULD SHAPE YOUR APPROACH
Erosion of trust — a regimen they believed in has failed	→ Rebuild confidence gradually; acknowledge the setback before introducing new options.
Grief or frustration over lost time and side effects endured	→ Validate these feelings explicitly. This reaction is normal, not a barrier to care.
Decision fatigue — being asked to choose again while depleted	→ Simplify the information architecture; lead with what matters most, not an exhaustive menu.
Recalibrated priorities — QoL, independence, family time	→ Never assume priorities are unchanged from the previous line. Ask again, every time.
Heightened body awareness — they know which effects disrupted life	→ Use their toxicity history as a shared reference point when comparing regimens.
Accumulated treatment workload across lines of therapy	→ Assess workload-capacity balance explicitly; a patient near their limit needs minimal disruption.

THE TREATMENT-BURDEN LENS

When you present options you compare the daily-life footprint of each regimen — clinic visits, monitoring complexity, hospitalisation, disruption to work and caregiving. A plan that is medically optimal but practically impossible will fail.

PROTECTING THE CONVERSATION SPACE

- ☑ Flag high-stakes consultations in advance and allocate extra time.
- ☑ Eliminate distractions — close the door, silence alerts, make eye contact.
- ☑ Normalise multi-visit decisions; not every choice must be finalised today.
- ☑ Use written or visual summaries the patient can revisit at home.

POST-CONSULTATION SELF-CHECK

Did this conversation cover what matters?

A brief mental review after r/r CLL consultations. Tick what you did — nothing is saved, this clears the moment you leave.

0/11

Ask 0/3

- [ ] Made it clear the patient's perspective is essential to shaping the plan
- [ ] Informed the patient about the treatment options available at this stage
- [ ] Found out what the patient already knows or believes about their options

Listen 0/4

- [ ] Learned what matters most to this patient right now — not last year, not at diagnosis
- [ ] Acknowledged the emotional weight of the moment
- [ ] Assessed the patient's treatment workload and capacity for additional demands
- [ ] Checked that the patient understood the information I provided

Offer 0/4

- [ ] Asked which option felt right for them given everything we discussed
- [ ] Confirmed the patient's choice and screened for practical obstacles
- [ ] Presented numbers in a way the patient could genuinely use
- [ ] Set up a clear plan to revisit this decision

The goal is a conversation that feels natural while ensuring no critical dimension is missed.

BACK TO OVERVIEW