The US Liver-Cancer Patient & Caregiver Journey: From Diagnosis Through Second Line and Beyond, and Where It Gets Stuck

> This report describes what patients and caregivers say in public online posts. It is not medical or investment advice and makes no judgment about the efficacy or safety of any treatment. Treatment names mentioned are used only to indicate which stage of the journey a discussion is in. Adverse-event mentions are counted, never quoted.

Executive summary

Based on 2,369 public posts from US liver-cancer patients and caregivers (355 from patients themselves, 2,014 from caregivers), posted between November 2025 and November 2026, each read by AI (up to the first 6,000 characters) and coded post by post; a random sample of 100 was re-checked by AI (first 900 characters each).

1. **This journey is told mostly by caregivers (85% of posts).** Of the 2,369 posts, 2,014 were posted by caregivers and only 355 by patients themselves. The most common burdens in caregiver posts are emotional strain (1,309 posts) and money (315 posts). *What this means for you: the first reader of patient education and support materials is often a spouse or adult child — write materials, hotlines and navigation services for them, not only for the patient.*
2. **Cost and insurance are the single most common blocker, and they show up from the moment of diagnosis.** 388 posts describe cost or insurance difficulty, the top blocker across six categories; 261 of those occur at the diagnosis stage, many of them fundraisers for treatment, travel or daily living costs. *What this means for you: financial assistance and insurance navigation can't wait until a prescription is written — reaching caregivers right after diagnosis is the only way to catch their earliest anxiety.*
3. **After first-line treatment there is an information vacuum (7 of 14), and it is being filled by non-standard options.** Of the 14 posts that name a specific next step after first-line treatment, 7 are antiparasitic drugs or other non-standard alternatives; such options are mentioned 50 times across all posts. Only 28 posts discuss second line or later (too few to break down further). This report only counts mentions; it does not evaluate the efficacy or safety of any option. *What this means for you: patients rarely find second-line information on their own — medical affairs needs to lay out evidence-based later-line options through treating physicians and patient organizations before first-line progression, or the gap gets filled by options outside standard care.*
4. **By the time patients reach palliative or hospice care (21% of that stage's posts), the most common theme is being told there are no further treatment options.** Of 341 posts about palliative or hospice care, 71 describe being told, or coming to believe, that no further treatment is available — the single biggest blocker at this stage. *What this means for you: posts about moving to hospice often also mention having no options left — offering referral information for later-line treatment and trials before this point, while also being clear about palliative support, are both gaps today.*

5. **Clinical trials rarely come up in patient and caregiver discussion (2% of posts), and the path to finding one is not clear.** Only 36 posts mention clinical trials: 12 already enrolled, 11 searching, 7 considering; 24 do not say where they learned about the trial, and only 6 say a doctor told them. *What this means for you: clinical operations cannot rely on patients finding trials on their own — recruitment needs to go through treating physicians, cancer centers and patient organizations, and needs to appear by the time of first-line progression.*

Journey map and five key questions

Posts per stage, and the top blocker at each stage.

Stage	Posts (n)	Top blockers
Diagnosis	1,441	Cost & insurance 261 · Waiting 160 · Side-effect management 144
Local treatment	231	Side-effect management 44 · Cost & insurance 42 · Waiting 34
Liver transplant	200	Waiting 71 · Cost & insurance 43 · Not enough information 22
First-line systemic treatment	237	Side-effect management 74 · Cost & insurance 46 · Not enough information 34
Second line and beyond	28	Can't find a next step 10 · Side-effect management 8 · Not enough information 5
Palliative / hospice care	341	Can't find a next step 71 · Side-effect management 54 · Cost & insurance 42

The discussion is heaviest at both ends and thin in the middle: 1,441 posts at diagnosis, 341 at palliative/hospice, only 28 at second line and beyond.

Five key questions

Question	n	One-line answer
What steps do US liver-cancer patients go through from diagnosis to second line and beyond? What does each stage discuss?	1,740	Discussion clusters at diagnosis (1,441) and palliative/hospice (341); the steps in between get little discussion.
Where does each step get stuck — cost & insurance, side-effect management, waiting, not enough information, or can't find a next step?	1,063	Most common is cost & insurance (388 posts); at the palliative stage it's mostly that patients and caregivers can't find a next step.
After first-line immunotherapy combinations, how do patients and caregivers find the next step? How much do they know about second-line options?	57	Too few posts to conclude: only 14 name a specific option after first-line; 15 say they were told there's nothing more to try.
What do caregivers carry, and what help do they need most?	2,014	Most common burden is emotional strain (1,309 posts); most-needed support is emotional support (423 posts).
How do patients and caregivers feel about clinical trials — how do they find one, and why do they join or not?	36	Too few posts to conclude: of 36 mentioning trials, some are enrolled, some searching, some considering; most don't say where they learned about the trial.

Methodology

Public English-language social posts, November 2025 to November 2026. 2,369 patient and caregiver posts included, each read by AI (up to the first 6,000 characters) and coded. 100 posts randomly sampled and re-checked by AI against the first 900 characters of each (accuracy reported on the full version's methodology page).

Conclusions & recommendations

Unmet needs (8 categories, posts could name more than one; share of all posts):

Category	Posts	Share
Emotional support & peer support	461	19%
Cost & insurance navigation	383	16%
A clear explanation of diagnosis, stage, prognosis and options	192	8%
Practical help and respite for caregivers	144	6%
Side-effect and symptom management	121	5%
Guidance on next-line treatment and trials	95	4%
Planning and support for palliative/hospice care	80	3%
Finding a liver specialist, transplant center or second opinion	45	2%

The two largest categories are emotional support & peer support (461 posts) and cost & insurance navigation (383 posts); guidance on next-line treatment and trials is only 95 posts (4%).

What this means by function

- **Medical affairs** — public discussion of second line and beyond is only 28 posts: the information gap on later-line treatment sits mainly between the treating physician and the caregiver. Prioritize educating community oncologists on later-line options right after first-line progression, and prepare caregiver-readable explanations.
- **Brand and patient services** — caregivers are 85% of posts, and cost/insurance is the top blocker at 388 posts: assistance and insurance navigation needs to reach caregivers right at diagnosis; hotlines and materials should be written around a caregiver's actual questions (money, travel costs, time off work, how to talk to the doctor).
- **Clinical operations** — only 36 posts mention clinical trials: patients rarely find trials on their own. Recruitment needs to rely on referring physicians, cancer centers and patient organizations, and recruitment materials should include travel and lodging support.
- **Biopharma companies preparing to enter the US liver-cancer market** — specific drug names are almost never mentioned in public patient-side discussion; caregivers mostly use generic terms like chemo or immunotherapy rather than brand or molecule names. Before entry, build an information and assistance channel aimed at caregivers, not only physician-facing promotion.

Limitations & how we address them

- **Small sample for second line and clinical trials.** The time window could be extended to 24 months, or patient-forum and patient-organization public discussion boards could be added and re-pulled.
- **Geography is not always certain.** A sensitivity check could keep only posts that explicitly name a US location or US insurance, and compare whether conclusions change.
- **Caregiver perspective dominates.** Longer patient-authored posts (for example, from forums) could be added to balance the perspective.
- **The blocker field has the lowest accuracy of all coded fields.** A further 100-post review could refine judgment rules such as whether a minor discomfort counts as a blocker.
- **A small number of non-US posts are mixed in.** Screening could require text evidence of being in the US, or posts that don't state a location could get a separate sensitivity check.

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For the full report, or a version built around your own therapy, contact martin@buyerlore.com.