

# **MEET LORI T**

## **University of Michigan Family Journal**



**We Care. She Cares.**

**Personal History Redefined**

An Introduction to the Reassessment Wheel

**By Al Timberlane**

# With Thanks to the People Who Cared

Before I tell the difficult parts of this stay, I want to thank the doctors and medical professionals who have cared for Lori, both at the University of Michigan and across the years that brought her here.

Thank you to the surgeons, physicians, nurses, therapists, pharmacists, technicians, and the people working to arrange medicines and care for home. We recognize the knowledge, effort, and responsibility that your work requires. Many of you brought brilliance, patience, reassurance, and kindness into our daughter's life.

Thank you to the male nurse administrator who brought the doctor back and encouraged him to hear our history. Thank you to the surgeon who returned for a final evaluation, explained wound care, and remembered Lori's room for its great vibes. Thank you to Sarah for her encouragement, to the volunteers who spent time with Lori, and to the friendly worker whose conversation about a dog gave us a reason to laugh.

We also remember the earlier physicians and children's hospitals that kept looking for ways to help. Their work remains part of Lori's history, along with the continuing knowledge of her outside primary doctor, whom we will not name.

To Lori, Becky, Morgan, and everyone who stood beside her: thank you for the time, love, and patience that cannot be reduced to a treatment list. Legend belongs in that circle too.

Our questions about the final plan do not diminish the care we received from so many people. I have written this manuscript to preserve our experience, to thank those who helped, and to ask how the connections in care might become clearer for the next patient and family.

The hope for this hospital is great. We want its future to include the whole person and the history that person brings.

Al Timberlane

# About This Manuscript

This book centers on Lori's University of Michigan hospital stay as experienced and discussed by our family in October 2026, through discharge. Earlier care appears where it explains our bedside concerns. It is a family narrative, told by her father, rather than a complete medical chronology.

Our corrected count for the admission is twenty-nine days. We had expected two or three. We describe nearly forty years of care, including gastroparesis and NF1 since birth in the family history. Questions about the cause of particular symptoms remain questions for individual clinical evaluation.

I arrived with Becky for the final week. Earlier episodes draw on family reports, correspondence, and recollections. Recalled dialogue is not a certified transcript. Dates and times printed on earlier letters remain unchanged; a notification call is not treated as the exact time of a procedure.

The illustrations are established AI-assisted pencil sketches and reconstructed scenes developed for this project, with selected wheel artwork. They accompany the narrative rather than document procedures or confirm staff likenesses. The assessment wheel is my proposed communication system; showing it on an iPad does not mean the hospital implemented it.

Lori's outside primary doctor remains unnamed. The book describes our observations, impressions, gratitude, and concerns. It does not claim knowledge of clinicians' private thoughts or turn an earlier hypothetical courtroom exercise into an actual finding.

The last pages preserve the questions we carried home and identify selected background sources. This is a working manuscript for review and refinement. Its center remains Lori: an adult with her own voice, a history, a sense of humor, and a life beyond the hospital.

For Lori, and for the people who keep listening.

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## Chapter 1

# Two or Three Days Became Twenty-Nine



Illustrative reconstruction

The stay was supposed to last two or three days. That was our family's understanding when Lori entered the University of Michigan Hospital. By the time we prepared to leave, it had lasted twenty-nine.

This book centers on her hospital experience in October 2026. The room, the procedures, the conversations, the people who helped, and the final plan for home form its story. The years before this admission come into it because Lori brought those years with her.

Her history includes gastroparesis and NF1, with health challenges reaching back to birth. Forty years of care stood behind the questions we asked at the bedside. We were trying to understand what that history meant for the decisions being made now.

Twenty-nine days can sound like a single length of time. Inside the hospital, each part of it had its own work: healing, waiting, trying medicines, listening to explanations, and wondering when home would be possible.

Our family remembers this as her third or fourth hospitalization that year. That uncertainty about the count of admissions does not change the count we settled on for this stay: twenty-nine days. The dates on earlier letters remain the dates on those letters. I will not move them into October to make the calendar simpler.

I am telling the story as Lori's father. Some parts came to me through her and the family; others I witnessed after Becky and I arrived for the final week. Our recollections belong beside the medical records, which can establish details that a conversation or photograph cannot.

What I remember most strongly is how the question changed. At first we expected a short stay and a return to familiar care. By the end we were asking how Lori would manage at home without the vascular access that had been part of her treatment for so long.

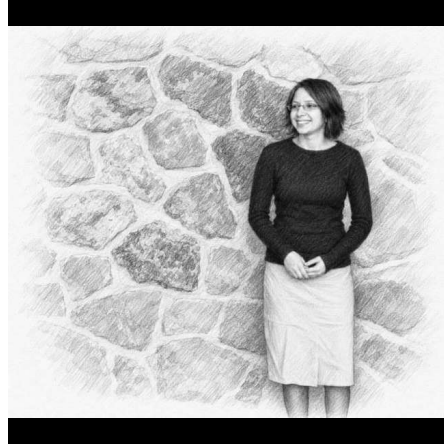
In between, there were people we will remember with gratitude. A male nurse administrator helped reopen a difficult conversation. A surgeon returned to explain the wound and told Lori that her room had great vibes. Volunteers spent time with her. Legend came for the day. There was laughter alongside the worry.

I want to tell all of that. The disagreements need enough detail to be understood, and the kindness needs enough room to be remembered. This is the account of a particular stay, in a particular hospital, with our daughter at its center.

Meet Lori T.

## Chapter 2

# Meet Lori



Illustrative reconstruction

Before there was a hospital story, there was Lori. There still is.

She is my daughter, nearly forty years old, a grown woman who can speak for herself. I know that, and I need to remember it when fear makes me see only the little girl I once watched grow up. Being her father gives me memories and responsibilities. It does not give me ownership of her voice.

In October 2026, we were trying to understand the final plan for a stay that had grown from an expected two or three days to twenty-nine. Our family remembers it as her third or fourth hospitalization that year. Her history of gastroparesis and NF1, with health challenges since birth, reached back across nearly forty years of care.

For years, illness has required room in her life. It has affected eating, strength, treatment, travel, and the ordinary decisions people make without much thought. Yet an account that begins and ends with symptoms would introduce her badly. Lori makes friends. She laughs. People enjoy being around her. During this hospital stay, a surgeon would tell her that her room had great vibes. An environmental services worker would stop to talk, and a conversation about a dog would make us laugh.

Those moments belong at the beginning of this book, even though some happened near the end of the stay. They tell you whom we are trying to keep in view.

I am Al Timberlane, a writer, producer, systems analyst, and father. In this story, the last of those roles is the one that keeps me awake. I want my daughter to have a good life at home. I want her able to take part in her own days, with care that takes her difficulties seriously and gives her a way forward.

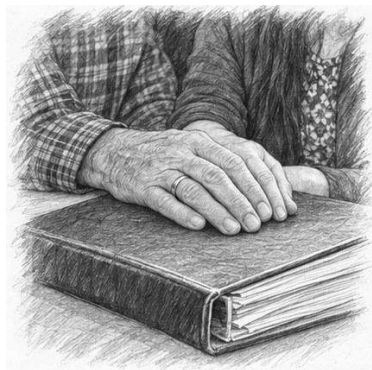
Becky and I came from Mountain View to help during the final week. We would listen, spend time with Lori, and try to understand what came next.

Becky and Morgan are part of the family account. We sat with Lori, listened, asked questions, and tried to understand what was happening. Legend, her service animal, belongs in the account too. His presence reminds me that support is often practical and personal long before it becomes a topic in a hospital conference.

This book grew from spoken recollections, letters, questions, and illustrated scenes. At first we called it *The Big Fish Story*. The fish described an explanation that seemed to grow while our understanding did not. As the writing continued, I wanted the person to stand ahead of the metaphor. The title became *Meet Lori T*.

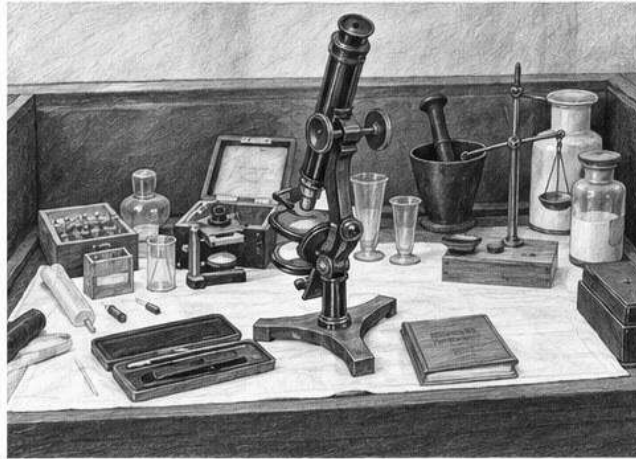
We were grateful for many of the people who cared for her. We also left with concerns about whether the final plan adequately reflected her history. Those experiences occurred in the same stay. I will not erase either one to make the other easier to tell.

The story begins with a life that was already underway when Lori entered the hospital. It follows that life to the point of leaving. What happens after that remains a question we will have to live, rather than an ending I can manufacture here.



## Chapter 3

# The hospital remembers



Illustrative reconstruction

The hospital has a history of its own. We photographed some of it behind glass: old instruments, containers, furniture, and rooms arranged to preserve an earlier world of care. The objects belonged to a story much larger than this admission. Looking at them, I thought about how many families had arrived before ours, each with a reason for hoping the university could help.

Michigan Medicine's historical account traces the medical school's first students to October 1850. It describes support from the university and Ann Arbor citizens for an expanded Medical Building, and a professor's former house opening as a twenty-bed hospital in December 1869. [R5]

That connection between a community and a school mattered to me. People helped build a place where learning could become care. Lori came here with that same hope: that knowledge, experience, and attention could meet the needs of a person.

The photographs preserve what we saw in the exhibits. I do not assign an unidentified object or photograph a date that its label has not established. A room displayed as history is also different from the operating rooms in which Lori received treatment. These pictures belong to the hospital's remembered past.

But the reflection they prompted belongs to the present. Institutions preserve their history because earlier work helps explain what they have become. Patients carry earlier work too: examinations, treatments, failures, improvements, and the observations of people who stayed with a problem over years.

A patient's recollection needs examination alongside the records. It may be incomplete. So may a chart separated from the people and events that gave it meaning. Our request was to bring those sources together and explain what they meant for today.

Respect for this university's history helped sharpen that request. We wanted Lori's history to remain visible as responsibility moved from one professional to another. In the large story of the institution, each individual patient still matters.



## Chapter 4

## Rooms for a community



Illustrative reconstruction

Beyond the room were other places to be a family. Our photographs show chairs, broad windows, open space, and colorful forms hanging overhead. A lounge could give patients and visitors somewhere to meet and a different view from the one beside the bed.

These places belong in the story. A hospital stay takes place partly in clinical conversations and partly in waiting, sitting together, finding a chair, and trying to absorb what has just been said. People arrive carrying coats, bags, questions, and lives that have not stopped outside the building.

I wanted the book to move through those spaces: the historical displays, the lounges, the real hospital room, and the doors beyond which procedures take place. The photographs show some of those places directly. The drawings help accompany the parts of the account for which we have no photograph.

The artwork gave us something to look toward beyond equipment and paperwork. The windows admitted a wider world. These details did not answer a medical question, but they were part of living through the questions.

That is what I mean by life in the big hospital. It includes expertise and buildings, but also the experience of the person who must stay there and the people who come to be with her. The community's hopes for the school meet the patient's hopes for the next day.

The reassessment wheel grew from my effort to make those connections visible. A list of specialties cannot by itself explain a life. The personal history needs a place alongside the hospital's current knowledge, with a way to identify what has been reviewed and what still needs an answer.

We did not want the university to become less ambitious. We wanted its ambition to reach the difficult, particular history sitting in front of it. The rooms, the research, and the community support all led back to that purpose: helping a person live.



## Chapter 5

# They wheeled her in



Illustrative reconstruction

They wheeled her in. They removed her port. They wheeled her out with a PICC line.

That was how I described the change. Our family understood the new line as temporary support while her body recovered, with the expectation that her continuing needs would still be met. We entered this part of the story with that understanding. We did not have the complete procedural account in front of us.

We were told insertion had been difficult and that another physician had been consulted. Our later letter asked the team to review the original report and that consultation. I had concerns about the size of the vein and the catheter, but concern was not a measurement. The people performing the procedure had findings we needed explained.

A family can agree that a procedure has occurred and still misunderstand what it means for the next stage of care. I wanted to know whether temporary access led toward replacement access, a different route, or a change in the whole treatment plan.

The need for care came back into the room with Lori. It did not stay behind the procedure doors. That was the point I kept trying to make when the story became focused on whether a particular device should remain.

As the admission continued, dates became crowded with events. Our final family count was twenty-nine days, after earlier estimates of nearly a month. I do not use that recollection to calculate an exact admission date. The September letters give firmer dates for particular communications, but they do not supply a complete daily hospital record.

What our family remembers clearly is the expectation that there would be a connected plan. We were prepared for treatment to change if the reason and the alternative were explained. We were frightened by the possibility that removing one problem could leave the daily needs behind it unanswered.

The first questions were therefore about the line and the procedure. Soon they became questions about pain. That change in emphasis matters. We were no longer discussing an abstract preference for one kind of access. Lori was describing something happening to her while the line was in use.

We wanted the earlier procedural difficulty, the current complaint, and the next decision brought into the same conversation. From the family's side of the bed, that seemed a reasonable place for reassessment to begin.

## Chapter 6

# The pain she described



Illustrative reconstruction

Lori described pain that she felt was far beyond what she could tolerate. I remember reports in the eight-to-ten range. I remember concern about pain during infusions and what she was feeling around the affected area. She was the person experiencing it; we were trying to make sure her account reached the people who could assess it.

I cannot turn a pain score into a diagnosis. It can tell a reader how distressing the experience was without explaining its cause. We needed both questions addressed: what she was feeling, and what was happening clinically.

The family also observed what looked like roughly two inches of outward movement in the catheter. That became one of the details we repeated. External movement alone does not tell me where a catheter tip is inside the body. It did give us a concrete change to bring to the team and ask about.

We wanted to know what had been checked, how it had been checked, and why continued use was considered appropriate.

There are several questions inside that request, and they should stay separate. Had the line moved externally? What did the examination or imaging show? Was it intact and in an appropriate position? Did any finding explain the pain? What action followed the assessment?

When I later tried to tell the story quickly, I could hear those questions collapsing into a conclusion. The line had moved, Lori had pain, and a collection was identified later. The sequence frightened us. It did not, by itself, prove the mechanism connecting those events.

We wanted the people with the records and expertise to examine that connection. Asking for an explanation was not the same as claiming we already had one.

Still, a careful account must not become so cautious that Lori disappears from it. She was telling people she hurt. Repeatedly explaining pain is work, especially when a person is already exhausted. The fact that her account could not settle every clinical question did not make it irrelevant.

I wanted someone to join her words to the findings and tell us what that comparison meant. If the assessment was reassuring, what made it reassuring? If the pain persisted, what would cause the team to look again?

These were the questions that brought us back to the earlier idea of reassessment. The plan needed a way to respond when the patient's experience and the explanation did not seem to meet.

We were concerned about Lori's severe pain following the difficult PICC placement, particularly after the line appeared to move outward approximately two inches. Given her small veins, we wanted the vascular-access team to reassess the cause of her pain, confirm the catheter tip's position, and explain whether the line could safely remain in use during that assessment. We also wanted to understand whether a smaller catheter could safely fit the same vein while delivering the fluids and medicines she needed. If that was not appropriate, we asked what alternative would best meet her needs, including whether the reported blockage in her left arm could be addressed to provide a safe route for access or whether that arm should be avoided.

## Chapter 7

# When reassurance did not settle it



Illustrative reconstruction

We were told that no clot had been identified. We understood that the line had been assessed as functional or usable. In the family conversations, the earlier description sometimes became "loose but safe." Those were the explanations we remembered hearing, not a substitute for the assessment itself.

Lori continued to report pain. We remained concerned about the outward movement we believed we had seen. The absence of a clot answered one question. We wanted to know how the other observations had been evaluated.

Our first September letter said we had been informed that interventional radiology was not planning further bedside evaluation or removal at that point. It also acknowledged that we had not seen the communications among departments. That acknowledgment was important. We did not know whether a particular clinician had refused a request, whether another team was responsible, or whether information had changed.

From the family's side, we needed a clearer account of who was reviewing the situation and what would happen if Lori's pain continued.

It is tempting, when telling a painful story, to make the explanation simple enough to name a villain. We could have said one department would not help or that someone had decided the matter was closed. Our letters tried to ask what had actually happened between the teams.

The people caring for Lori were not all in the room at once. One person could know a procedure, another a scan, another the patient's pain over a shift. Our concern was whether those pieces had been compared before the next decision.

I wanted an answer I could follow. If the line was considered usable, what supported that conclusion? If another finding explained the pain, what was it? If no explanation was yet available, what was the plan to investigate it or make her more comfortable?

That was where the fish metaphor began to feel useful. The explanation could grow in length without resolving the question that made us ask it. I was not claiming a real fish or presenting a scientific theory. I was describing the distance between the reassurance we heard and the distress we were witnessing.

The metaphor needed limits. It should not turn every clinician into a character in a joke. The stakes were our daughter's life and comfort, and many people were trying to help. We needed the telling to remain large enough for those people and exact enough for the questions.

## Chapter 8

# The letter and the telephone call



Illustrative reconstruction

The September 26 advocacy packet preserves a sequence more carefully than my memory alone can.

The first letter carries the time 3:25:07 p.m. CDT. It requested urgent reassessment of Lori's painful PICC line. It asked for review of the insertion report, the catheter site and position, the ongoing pain, and communication among the relevant teams. It described our concerns as matters for medical evaluation, not established diagnoses.

At approximately 3:29 p.m., we received a telephone call saying that the line had already been removed after another reassessment. The packet is explicit about an important distinction: 3:29 was the time of the call. It was not the documented removal time.

The follow-up letter, prepared at approximately 3:30 p.m., acknowledged that the situation had changed. We appreciated that professionals had reassessed Lori and taken action. We also asked what came next.

Those timestamps are preserved as printed in the correspondence. They should not be silently converted into a bedside chronology or used to establish an exact procedure time.

Medical staff removed the PICC. Lori did not remove it herself.

Our understanding was that a team involved in vascular access and blood draws had removed the line following involvement by treating physicians and nurses. We had not confirmed the team's formal name or precisely how interventional radiology had been involved immediately beforehand.

The later letters asked for those details. They also described several days of pain and our recollection that roughly six days had passed before removal. That interval belonged to our account and needed comparison with the clinical record.

We were relieved that the existing catheter was out. We still wanted the reason documented, the symptoms reassessed, and the original procedure understood. Removing a line could settle whether that line remained in place without settling why it had hurt or how Lori's continuing needs would be supported.

The packet asked whether a smaller PICC or another site or form of access might be appropriate. We recognized those as clinical decisions. We wanted someone to connect Lori's vascular history and insertion difficulty to the available choices, including whether a plan would work at home.

The fourth letter explained why the first three should remain together. A reader seeing only the first might think we did not know removal had occurred. A reader seeing only the second might miss the pain and concern that came before it.

That small problem of document order was an example of the larger problem troubling us. Information changes meaning when the surrounding history is lost.

## Chapter 9

# The problem we called Big Bertha



Illustrative reconstruction

We called the frightening area on Lori's chest Big Bertha. The nickname gave the family a way to refer to something that hurt and worried us. It did not identify what the area contained or what had caused it.

I described it as round and black, approximately five centimeters across. It was on the front of her upper left chest, just below the collarbone. I corrected earlier drawings that had put it on her back. Location mattered because we were trying to explain what we had seen, not invent a dramatic mark wherever an artist found room for it.

During the stay, we had questions about swelling, pain, bleeding, and the explanations we were receiving. Later, Lori clarified that the surgeon had removed a collection of blood and explained that she had a hematoma. That clarification is important to the way this book tells the story.

Big Bertha is our name for the problem. It is not a diagnosis of a neurofibroma, a cancer, or a medication injury.

Our concern was partly about how the events connected. There had been a port, a PICC, pain, a changing chest area, and procedures. We wanted to know what relationship, if any, the records and findings established among them.

The order in which we experienced events made a connection seem possible to us. It did not prove one. If a clinician believed the problems were unrelated, we wanted the reason explained. If there was a connection, we wanted to understand what had been found and how that affected the next stage of care.

I also remember concern about bleeding and the family understanding that cautery had been used. The operative details, the timing, and the reasons for specific treatments belong with the reports. The book can preserve why we were alarmed without claiming to reconstruct a procedure from the waiting room.

The nickname sometimes made room for humor, as family nicknames do. Underneath it was Lori, living with pain and a wound that required attention. When we later said the wound was water under the bridge, we meant that we were trying to move the conversation toward her continuing needs. We were not saying that its history should be erased.

The surgeon's return at discharge would bring part of this episode back into focus. He would explain the hematoma and wound packing. For now, the family was still asking what had happened and waiting for answers that made the course of care understandable.

In another family discussion, Lori said that the medicine given for dressing changes was not meaningfully relieving the pain. She described the dose as very small. A physician indicated that he would put in an order to try something more because the current dose was not enough. We did not yet have a medication order or a result to report from that statement.

There was improvement too: Lori said the bleeding had gotten much better. We recognized that as welcome progress while continuing to ask about comfort during wound care.

## Chapter 10

## Outside the procedure room



Illustrative reconstruction

Procedures can divide a family's attention. One part is fixed on the immediate problem: what must be done now? Another part remembers what happened before and fears its return.

Lori reported a prior cardiac arrest during a procedure under anesthesia or sedation at another hospital. I recalled doctors informing me of that event. In our advocacy writing, we asked the present team to obtain the relevant records and have anesthesia review the history before another procedure.

She wanted general anesthesia. That request arose from her experience and fear, including concern about pain and distress. It did not settle which approach was safest. We wanted the people responsible for anesthesia to consider the history and explain the choice and safeguards.

Earlier conversations included discussion of moderate sedation and the measures that might accompany it. The exact drugs, monitoring, and decisions should come from the anesthesia record. I will not turn an anxious family discussion into a verified account of what was administered.

Waiting outside, we were trying to understand what had been found and what would happen next. Had material been removed? How was it described? Was any further evaluation planned? Would the result change the explanation of the wound or the plan for access?

A procedure could address an immediate problem while leaving our broader questions open. We needed a connected account afterward, one that did not assume the family understood the clinical language because we had been through many hospitals before.

Long experience can make families familiar with terms without making them experts in every procedure. We had memories of what Lori had tolerated and what frightened her. The team had responsibilities and information we did not possess. Bringing those together was the task.

When I spoke sharply, I was often trying to make sure a past danger was not treated as an old story with no relevance. But my fear did not establish that a proposed approach would repeat it. The earlier records and a present assessment were needed for that judgment.

What I wanted was specific: please explain how her prior experience had been considered, why the selected approach was appropriate now, and how her pain and distress would be managed. Those questions were part of our request for individualized care. They were not an anesthesia plan written by her father.

The family advocacy letter supplied for this manuscript preserves another detail of the aspiration attempt. It reports that approximately 12 cc of dark, old-appearing, non-purulent fluid was obtained and sent for analysis. It describes procedural documentation indicating that severe discomfort prevented aspiration of another, smaller compartment. We have the family's letter here, rather than that procedure report itself.

The letter records a plan to reschedule with a different pain-management or anesthesia approach. We appreciated that reconsideration. The limitation of the first attempt was information for the next plan. Lori had discussed her fears, agreed to try the procedure, and continued working with the team afterward.

## Chapter 11

# The words that needed explaining



Illustrative reconstruction

I remember hearing material described as ooze. It was a word we could repeat without understanding much more than before.

What was it? Where had it come from? Had a sample been collected? Were there culture or pathology findings? Did the results explain the pain, swelling, or changes we had seen?

We did not know the answers simply because we had not watched a sample being collected. Not seeing a test performed is different from knowing it was omitted. Our written questions asked what the records showed.

We also remember being told about a staph infection. We wanted to understand what specimen had supported that explanation, when it had been obtained, and how the finding changed treatment. The organism, source, and timing require the laboratory and clinical records. Our account does not independently establish where an infection began or how it related to every later problem.

The later explanation of a hematoma added another piece. It did not authorize us to assume that every earlier term had described the same thing.

In a hurried telling, a wound, blood collection, infection, catheter problem, and medication concern can become a single event. We experienced them as connected worries. Clinically, each needs its own description before anyone can establish a relationship among them.

That is why our questions were sometimes repetitive. We wanted the source of an explanation, not another version of the explanation itself. What did imaging show? What did drainage show? What did a culture establish? What was still uncertain?

I am a writer, so words matter to me. A familiar word can make a complicated finding sound settled when it is not. A technical word can also be accurate and still leave a family without an understanding of what it means for the patient.

We needed someone to translate the findings into the next decision. If an infection had been identified, how was response being assessed? If a collection had been removed, what follow-up did the area need? If uncertainty remained, who would return to it?

The questions were not a claim that every complication was preventable. They were our attempt to follow what was happening to Lori. The more we understood the individual findings, the less we needed to rely on the growing fish story that had come to represent our concern.

Lori believed the infection had developed during the hospitalization. She said she had not experienced this kind of infection at home. That was her account and concern; the timing, source, and cause would need comparison with the clinical findings. When we discussed future access, we also wanted the earlier vascular history and concerns involving the superior vena cava, or SVC, considered in planning.

## Chapter 12

# Keeping medicine down



Illustrative reconstruction

As the hospital stay continued, the route of medication became a question about life after the room. Lori would be the one trying to take the medicine at home. She would be the one experiencing what happened afterward.

Our family observed difficulty keeping medication down throughout the stay. In the final account, I said it happened every day and that her nausea had never been fully brought under control from our perspective. That describes what we witnessed and experienced. The administration record and assessments would be needed to establish each dose, its retention, and the team's response.

Earlier questions also referred to a gastric-emptying result. We wanted to know how that finding addressed Lori's actual ability to take and benefit from the medicines being proposed. We asked about retention, suspected absorption difficulties, and whether further evaluation would clarify them.

Vomiting, absorption, and metabolism are different issues. Our observations did not establish a failure of the intestinal lining or show how every medicine was processed.

I had spoken more broadly in frustration, describing medicine being thrown up, thrown out, or sometimes trapped. A little humor entered the words because that is one way a family keeps speaking about a long, difficult experience. But the question underneath was practical: how would we know that the medicine was helping her?

We wanted an explanation of the proposed route, the expected response, and what would happen if she could not tolerate it. We were not in a position to select a test or insist that one result would settle everything. Our letters asked clinicians to explain what further testing might and might not establish.

The family's earlier experience with IV treatment made us doubtful about a plan relying on oral medicines. Doubt was a reason to ask for a careful explanation, not proof that a particular route was medically required.

We could agree to a plan and still ask how it would be reviewed. A useful plan needs a way to distinguish an unpleasant adjustment from an approach that is not meeting the patient's needs. Who would make that judgment outside the hospital? What information would reach that person?

These questions would become especially important near discharge. At the time, we were still trying to understand how the symptoms in front of us had been considered in the plan being prepared for home.

Lori was frustrated that vomiting after oral medicines still seemed to surprise people. She said the difficulty had been discussed repeatedly and had existed long before this admission. She was trying to keep the medicines down. It was not, she said, something she chose to do.

Our discussion notes record that nursing staff had witnessed vomiting, including after medicines. At times they reassured Lori that she did not have to keep showing or proving every episode because they already knew it was happening. The family nevertheless discussed recording the pattern consistently, perhaps on the room's whiteboard, so it would remain visible across conversations.

Lori connected the difficulty to her gastroparesis and believed delayed emptying and vomiting interfered with medicines remaining down and being absorbed reliably. We wanted that concern evaluated. Her experience of vomiting did not establish the absorption of each dose, but it was part of the treatment problem we needed the plan to address.

## Chapter 13

# The years we remember



Illustrative reconstruction

During the conversations about discharge, our minds returned to the years before this room. Lori's graduation photograph recorded an achievement. It also held a history the picture alone could not tell.

We were living in Harriman, Tennessee. She was so weak that she had to be pushed up in a wheelchair for graduation. She could walk at times, but she could become too weak to continue safely. A photograph of her standing against rocks came from around the same period. Standing for that picture did not mean she was well.

Our family remembers severe difficulties with nourishment. I recall a period when she weighed about ninety-five pounds. That is a remembered figure from an earlier part of her life, rather than a measured weight during this admission.

Around graduation, I believe a feeding tube was being considered. My recollection is that she later had a tube before receiving her first port at about twenty. Those details are part of the history we wanted brought into the present discussion. The earlier records could help establish the dates and sequence.

Roughly a year after graduation, Lori was generally walking without relying on the wheelchair as she had before. Improvement came over time, with ongoing care. We remember the port making a tremendous difference: access allowed medicines to be given in a way that helped control nausea and vomiting. We saw her keeping more food down and participating more fully in life.

That was the family's experience of improvement. It was why a conversation about removing access could never feel to us like a conversation about a device alone.

Later photographs showed Lori with her niece during a period when we remember her doing well. Others showed her as an older adult with Legend, her service dog. Each picture belonged to a different chapter, with care continuing between the photographs.

We also remembered weakness, fainting, and falls, including on stairs. Near Watts Bar, where we once lived, I remember her seeming so slight that a small tree could have hidden her. It is an image a father keeps. Lori reminded us that her weight fluctuates; the records could provide dates and measurements that memory could not.

These memories came into the October hospital room because we wanted to understand how the next plan would support her life. Earlier improvement did not answer every present question. It made us ask how the benefits we remembered had been evaluated, what had changed, and how the new approach would be reviewed if old difficulties returned.

## Chapter 14

# The doctors who kept looking



Illustrative reconstruction

As we explained Lori's history to the people caring for her now, earlier doctors became part of the conversation. We remember seeking help at at least three children's hospitals. I cannot compress all those encounters into a single discovery or pretend that every question was answered. What remains with me is the search itself and the professionals who kept taking an interest.

Dr. Gravenstein and Dr. Obi became names I returned to during the later discussions. They stood for care relationships that lasted long enough for a physician to know more than the immediate episode. I remember Dr. Gravenstein paying close attention to medicines, nourishment, and the possibility of a genetic contribution to Lori's difficulties.

In earlier telling, I spoke about his background and the personal reasons I believed he cared. The most important part for this account is simpler: I felt that he took Lori under his wing. He kept looking. The exact clinical conclusions belong with his records, not with my gratitude alone.

I wanted the people caring for Lori now to understand why those earlier relationships still mattered. A physician may no longer be available, but the care that occurred does not disappear from the patient's life.

Lori once said, as I remember it, that contacting an earlier doctor would not do any good. He was not her doctor now, and she felt that people did not care anyway. Hearing that hurt. I am her father, and I wanted to believe there was still a way to connect the people who knew her with the people responsible for her care today.

Her discouragement was real. It did not allow me to know what any particular clinician felt. There is a difference between describing how care was experienced and claiming access to someone else's mind.

That distinction became important as the fish metaphor developed. I imagined a different kind of fisherman, a doctor who asked us to bring in the fish we actually caught rather than make it larger in the telling. The fishing conversation was invented. The obligation underneath it was real: keep searching, and describe the problem accurately.

I wanted to apply that obligation to myself. If an earlier treatment helped, say what we remember and seek the record. If a doctor suspected a mechanism, distinguish a suspicion from a diagnosis. If I felt dismissed, describe the conversation and the effect without inventing a private motive.

The doctors who kept looking left us something useful even where the search remained unfinished. They showed us that a complicated history can be approached with interest. We wanted that interest to survive the changes in place, age, and responsibility that come with a long illness.

## Chapter 15

# What access had meant at home



Illustrative reconstruction

The word access became central to this hospital stay. To someone hearing our family for the first time, it might have sounded like we were talking about equipment. We were talking about the care that equipment had made possible, as we remembered it.

For approximately twenty years, Lori had generally had a port or another form of IV access. There had also been periods without access and changes in treatment. That is an approximate account, not an uninterrupted device-by-device timeline. We recalled her first port at about twenty and meaningful improvement with the care that followed.

Her vascular history had another chapter. We remembered substantial upper-body swelling, a weight gain of roughly forty pounds, and being told that blood was traveling through alternate veins around a problem involving her superior vena cava. We remembered cardiovascular treatment at the University of Michigan, including a stent more than fourteen years earlier and another later.

I called that my Houdini story: the body's alternate routes, as we understood the explanation. The nickname was a family metaphor. The anatomy, findings, dates, and procedures belonged with the cardiovascular records.

That circulation history mattered when we asked which routes could safely remain available now. Ports, PICCs, feeding tubes, and vascular stents were different parts of her care. Remembering them together did not make them interchangeable.

Lori had remained under medical care as physicians changed. A later primary doctor continued prescribing with an understanding of the history, as our family experienced it. The departure of an earlier physician did not remove that physician's work from Lori's life.

We were prepared to hear that access had become too risky. We needed to understand what would replace it, whether Lori could tolerate that alternative, and who would respond if she could not keep medicines or fluids down.

In my opinion, a decision becomes nearsighted when it concentrates on one complication without adequately reassessing the longstanding need and the consequences of leaving it unmet. That was our concern about the explanation, rather than a clinical conclusion that a new port must be placed.

What was the goal of trying a different route? How would success be judged? Who would review the response at home? We wanted the present reasoning connected to the earlier benefit we believed we had seen, with clear responsibility for the next step.

The port itself could not promise a good life. Neither could removing it. Our interest was in a workable plan for Lori, with the history connected to the assessment and the assessment connected to her life at home.

## Chapter 16

# The question of NF1



Illustrative reconstruction

Our family's account begins with NF1 since birth and a long history that includes gastroparesis. During this admission, we wanted the relationship between that history and Lori's current gastrointestinal difficulties examined carefully.

That was not the same as having established a mechanism. The question was how much NF1 might explain about her particular gastrointestinal symptoms and treatment experience. The records and specialist assessments could help distinguish what was established from what remained uncertain.

A relevant research paper gave us something more precise to discuss. A 2025 paper by John A. Damianos and colleagues examined gastrointestinal motility problems in people with NF1, including gastroparesis. It gave us a reason to ask about that connection in Lori's care, while leaving her particular cause and treatment needs to individual evaluation. The reference appears in the notes. [R4]

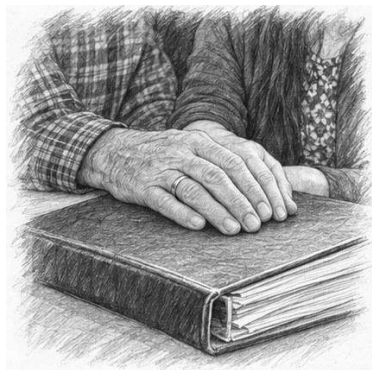
I wanted to know whether her history warranted further evaluation by people familiar with that possibility. If the present team believed it did not explain her symptoms, we wanted to understand the reasoning. If it remained a question, we wanted to know who would carry it forward.

We had also mentioned an older study in the family discussions. We did not raise the 2008 study during the final conversation with the doctor and the male nurse administrator. That detail matters because a rewritten account should not put arguments into a meeting where we did not make them.

Our interest in research was hopeful, but hope can become too certain if it is allowed to fill gaps in knowledge. I could not move from a paper about a group of patients to a conclusion about Lori without the intermediate clinical work.

Neither did uncertainty make the question meaningless. A family can live for years with a question that has not yet been resolved. We wanted a place for it in the plan, with someone responsible for deciding whether and how it should be investigated.

The genetics question would remain with us as we thought about future care. Perhaps a specialist here could help. Perhaps another institution could offer a useful review. What we needed at this stage was a connection between an unfinished question and the next person who could consider it.



## Chapter 17

# The doctor outside the network



Illustrative reconstruction

Lori had an outside primary doctor who knew her and had been prescribing IV medications. We will not name that doctor in this book.

Her involvement became important because the hospital's explanation eventually centered on the absence of a willing prescriber. Our family had a different starting point: there had been a prescriber, and there was a treatment history that needed to be understood.

Earlier family updates said that the outside doctor's prescribing changed after communication with the hospital. Later, when we were frustrated, we sometimes said simply that she was writing for the medicines. Those statements need a timeline rather than being placed beside each other as if they describe the same moment.

What we can say here is that she had been prescribing, and that our family understood her position to have changed following discussion with the hospital. We did not have the complete exchange or a current written statement of willingness in front of us. Her earlier prescribing did not, by itself, establish what she would prescribe at discharge.

That distinction does not remove our question. It makes the question more exact. What had been communicated? What information changed the recommendation? How had the earlier treatment experience been considered? Could the outside clinician and the present team explain the change together?

We wanted her knowledge treated as part of Lori's care history. We did not think an institutional boundary should make that knowledge disappear. At the same time, no outside physician's earlier opinion could automatically determine the present team's decision. We needed the reasoning that connected them.

In the final conversation, I chose not to keep repeating her name. I said to leave her out of it at that time because I did not want to put her in the middle of another disagreement. That was a decision about the discussion in the room. It did not mean we believed the outside history had become irrelevant.

The hospital doctor said he had spoken with GI and cardiovascular. We understood that he had also spoken with the outside doctor, with a nurse present, but he did not mention that call during the explanation we heard. The complete communication record would be needed to establish its content and effect.

What troubled us was the gap between a conclusion and the route taken to reach it. Saying there was no willing prescriber sounded final. We wanted to know how a history of prescribing had become that present position, and what alternative now met the needs the earlier treatment had addressed.

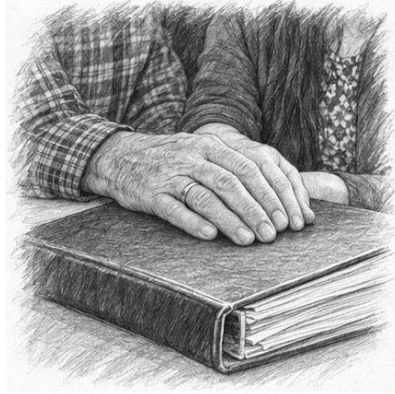
Lori felt that the earlier treatment approach had helped keep her stable and that it had been disrupted without a workable replacement. She questioned why opinions from clinicians with limited involvement in her long-term care had so much influence. She described only limited ongoing contact with GI and wanted to understand the role of that specialty's recommendations.

We wanted to speak directly with her primary doctor about the next plan. For this immediate conversation, the family chose not to involve another procedural physician. The purpose was to work out what could help Lori going forward and how the earlier treatment history had informed the change.



## Chapter 18

# A Producer's Tools for Being Heard



Illustrative reconstruction

I came to these conversations as Lori's father, and I also came as a writer and producer. I was accustomed to asking questions, listening to an interview, and finding a way for another person's experience to reach an audience. During this stay, those habits became part of our effort to explain what we were asking.

The first tools were words: questions, letters, and the short accounts we wrote as events changed. Earlier advocacy had called for individualized reassessment. I used Patient Zero to mean beginning with the particular person in front of the team. That was our proposed principle, rather than an established medical or legal term.

Then came the wheels. The hospital wheel showed the resources within the institution. Lori's wheel showed the history and relationships she brought with her. The reassessment app concept put those two views on a screen so that a family and a professional could look at the connections together.

The drawings helped us explain a question that had become difficult to say briefly: how could all that knowledge meet in the plan for one person?

Storyboards gave the account a sequence. A page could hold an arrival, a question, a conversation, or a departure. Sketches helped us keep Lori visible as the writing moved through procedures and disagreements. We revised scenes when a detail was wrong, including the male nurse administrator's role and the location of the chest problem.

Cartoons offered another way to speak. A short exchange such as listening to me and listening to you could carry a communication question in a few lines. Humor belonged to our family, but it needed care. A cartoon could express frustration without becoming evidence about what a clinician thought. Some images were taken down for review as the public presentation changed.

The newspaper-style articles and multimedia releases gave us room for more than one part of the experience. We could tell a difficult story about reassessment and also share kindness, volunteers, therapy animals, and the people who brought warmth into the hospital. In the hospital setting, we interviewed people involved with therapy animals. I will not supply names, quotations, or details that are not established in this account.

Our earlier musician interviews were part of the experience we brought to that work. Listening to artists had taught me how much a good question could uncover. Their place here is in explaining my approach as a producer; those earlier interviews were not all hospital encounters.

Legend's visit belonged to Lori's own life. He was her service animal, with a different role from the visiting therapy animals. Both could be part of the wider account without becoming the same story.

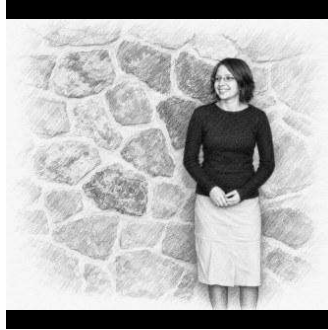
These tools helped us organize and communicate. The clinical questions still required records and professional judgment. My responsibility as producer was to keep the accounts accurate, preserve the warmth as well as the conflict, and help readers meet the person whose history we wanted heard.

In the Patient Relations letter, we described our perspective as wide-angle or cinematic. A specialist might see one procedure, a nurse a shift, and another doctor the next day's problem. We were trying to hold the sequence together. We did not claim to see every clinical discussion; we wanted someone with clinical responsibility to connect the whole course of care.

The full letter appears in the appendix. It preserves a request made while procedures and discharge planning remained unresolved. Including it here does not establish when it was sent or whether Patient Relations received it.

## Chapter 19

# The Patient's Voice and the Questions of Rights



Illustrative reconstruction

I used the word weight because I was trying to describe influence. How much weight did Lori's account carry? How much weight did the history carry? What happened when the patient said an approach had failed her before?

At one point I spoke as if "patient weight" were a legal term. That was not a careful way to put it. In this book it means the importance of her experience and preferences, not a separate legal doctrine giving her the power to order a treatment.

The legal questions mattered, and we sought information about participation in care, informed decisions, refusal, and discharge communication. Those questions are summarized with public sources in the reference section. The questions did not produce a legal finding about Lori's stay.

What I wanted in the room was practical. If Lori said she did not believe the plan would work, could that concern lead to a clear discussion of the reasoning and the next steps? Could she end a conversation with a particular doctor and still receive the essential information needed to leave?

Our earlier legal discussions also raised constitutional questions about liberty, dignity, and the voice of a person inside a large institution. I wanted to know what protections applied and what meaningful participation should look like. Constitutional analysis requires its own facts, including the relevant government action and the particular right involved. A disagreement about medical judgment does not answer those questions by itself. [R6]

Lori's adulthood matters here. A father's insistence can become so loud that even his concern takes up the space his daughter needs. I had to remember that she could disagree with me as well as with the doctor.

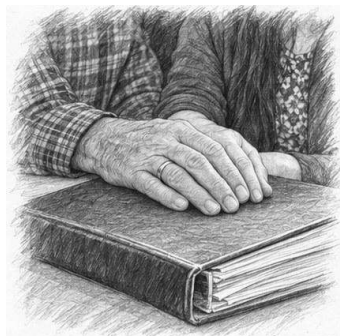
She could be tired of a conversation I wanted to continue. She could want to go home while I was still trying to establish one more point. Her choices did not erase my concern, but they set a boundary around what I could claim to be doing for her.

Earlier drafts and questions considered whether family members might be separated from a patient or cut off from discussion. That fear belonged to our concern about systems and communication. This account does not establish that Lori or her family was unlawfully confined or that a particular separation occurred. A story should not turn a fear into an event merely because the fear is vivid.

Nor should it turn a disagreement into a court judgment. We explored hypothetical legal arguments to understand the questions. An imagined attorney's closing statement, built on assumed proof, was not proof and was not an actual trial. Its assumptions do not become hospital history in this book.

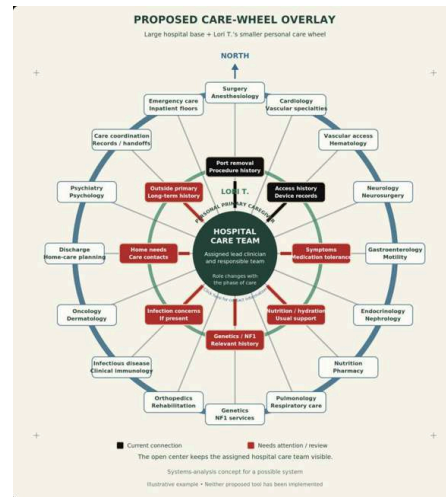
The useful question remained close to the bedside: had Lori received an explanation she could understand, a meaningful opportunity to participate, and a clear plan for what happened next? I wanted those things because she was the person who had to live with the result.

The family tried to keep one point clear: this should remain a patient-health reassessment. We did not want it to become a personality conflict, a contest between professional opinions, or a challenge between Lori and a physician. Symptoms, history, prior treatment response, and a plan for stability were the subjects we wanted examined.



## Chapter 20

# The Hospital Reassessment Wheel



The proposed reassessment wheel / illustrative concept

I began drawing the hospital as a wheel. The broad rim represented available services. At the center sat the assigned care team and responsible clinician. The drawing was a proposal for making relationships visible, not a claim that every patient needed every specialty. It helped me ask where information went when responsibility changed.

I have called it the hospital reassessment wheel, the reassessment wheel hypothesis, and the 30-Day Reassessment Wheel. Those names describe the communication proposal that grew out of this experience. Its question is whether making the connections visible could help the team bring a patient's history into the present assessment.

A hospital contains far more knowledge than one family can take in. Surgery, nursing, vascular access, GI, cardiovascular care, pharmacy, nutrition, genetics, and discharge planning may each hold something relevant to a complicated patient. A directory can tell us that those resources exist. It does not necessarily tell us how the relevant knowledge reaches the decision being made today.

On the wheel, the center needed a name or role that could change with the phase of care. The team responsible during a procedure might differ from the team responsible on the inpatient floor. At discharge, responsibility had to connect to people outside the building.

I did not intend the drawing to replace those clinical judgments or reorganize a hospital by itself. It was a way to make missing connections easier to discuss. If a spoke represented a useful service, had it contributed? If it had not, was that because its involvement was unnecessary, unavailable, or still unresolved?

Those are different answers. A blank connection should not make them indistinguishable.

The wheel also needed to respect the patient. It could not become a display so crowded with institutional boxes that Lori disappeared at the center. The system existed to support a person with particular needs. That person had to remain visible while the professionals did their work.

The larger wheel was only half of the proposal. It showed what the hospital could bring. It did not yet show what Lori had brought with her.



## Chapter 21

# The 30-Day Reassessment Wheel



The proposed reassessment wheel / illustrative concept

Lori's personal wheel was the other half. It carried her relevant history, outside care relationships, symptoms, treatment experience, and needs at home.

Not every patient would have the same spokes. A person with a short, straightforward history might need a very different overlay from someone whose care had crossed decades and institutions. The personal wheel was meant to make that difference understandable without requiring every new clinician to begin with an unstructured account of forty years.

Our example included procedure and access history, medication tolerance, nourishment and hydration concerns, relevant genetics questions, home contacts, and the outside primary caregiver. Those labels did not establish a diagnosis or require a device. They pointed toward information and people who could help answer the present questions.

The personal overlay had an open center so the assigned hospital team could remain visible beneath it. I wanted the history connected to responsibility, rather than placed beside it as an optional extra.

In the illustrations, we put the proposal on iPads and called it the Assessment Wheel app. The app was a concept, not a system already operating in Lori's hospital. Showing it on a screen was a way to imagine clinicians and families looking at the same information together.

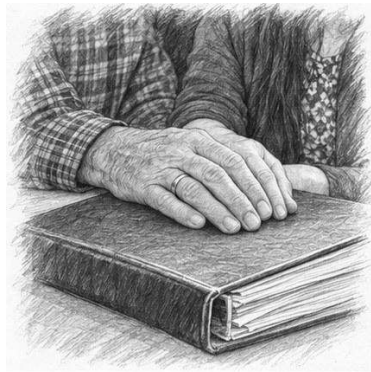
The exact wheel artwork mattered to me. A decorative circle would not explain the proposal. I wanted the spokes and labels visible so a reader could understand what might need review and who might hold the relevant history.

The colors in the example were illustrative as well. A current connection could be distinguished from an area needing attention. That did not mean a red item was a proven failure or that every colored spoke required a referral. A useful tool would have to explain the status, the source, and the reason behind it.

A future version would need safeguards for private records, accurate contacts, corrections, consent, and responsibility for updates. We had begun thinking about technology partners, but a promising screen would not settle those practical questions. Development would need patients, clinicians, and people who understood hospital workflows.

For our family, the immediate purpose was simpler. We wanted someone to take the personal history seriously enough to compare it with the hospital's present assessment and show us where the two agreed, where they differed, and what still needed work.

The thirty-day name recalls the nearly month-long experience that brought the idea into focus. Lori's corrected stay was twenty-nine days. The proposal needs practical development: a way to show what has been reviewed, what remains uncertain, and who will follow the patient beyond discharge.



## Chapter 22

## When the conversation narrowed



Illustrative reconstruction

Lori told us that she felt people downstairs had listened, and that the experience changed after she moved upstairs. She described being there for about two weeks. That was her account of how the conversations felt; I cannot use it to establish that no member of a team listened during that period.

She repeatedly said, "They don't care. They really don't." I heard the discouragement in those words. They described her experience of the stay, not a fact I could verify about anyone's private feelings.

I was frustrated too. Sometimes I called the situation intimidation. Lori corrected me. She said she was not intimidated; she was simply at the point of wanting to leave. Her correction matters. I should not substitute my description of her emotions for her own.

We were trying to tell a long history inside conversations that often returned to a present recommendation. The repetition became exhausting. We wanted to know which parts of that history had changed the assessment and which had been considered less relevant, with reasons we could follow.

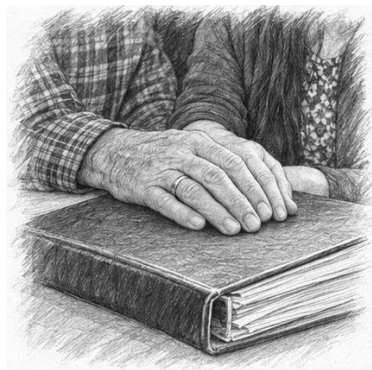
The fish metaphor could sharpen that frustration, but it could also make the story less fair if I used it to ridicule everyone in the room. The hospital contained people who helped. The physician whose conclusion troubled us could still believe he was acting responsibly.

I had angry things to say about stubbornness. I even reached for a mule as an image. That anger belongs to my reaction. It does not describe a clinical finding, and it does not explain a doctor's motives.

Earlier imagined scenes went further, picturing people wanting the story to disappear or thinking they would never see Lori again. Those were dramatic expressions of how the situation felt to me. They were not conversations we witnessed or thoughts we could know. They do not belong in a factual account as events.

What we could describe was enough: persistent symptoms as we observed them, a plan we did not feel addressed the history, and increasing fatigue in trying to explain why we were worried.

Lori could manage a difficult conversation and still decide it was no longer useful. Her wish to stop did not prove that the questions were answered. It told us something about where she was in the experience. I needed to listen to that as carefully as I wanted the hospital to listen to her history.



## Chapter 23

# From Mountain View to Her Bedside



Illustrative reconstruction

I paused my radio production work in Mountain View, Arkansas. Becky, my wife, and I flew to be with Lori. About six hours later, we were in Ann Arbor at her bedside.

We came for the final week of the admission. I cannot write as if I had stood in every room during all twenty-nine days. Lori and the family had already been living through the stay before we arrived. Some of what I knew came from their updates and the letters we had prepared; some I would now hear and see for myself.

Being at her bedside changed the scale of the questions. From a distance, we could discuss a treatment, a line, a procedure, or a discharge plan. In the room, every one of those subjects belonged to Lori. She was the person trying to heal and the person who would have to carry out the next plan.

We stayed and helped through that last week. We wanted time with our daughter, time to listen, and an opportunity to understand what was being arranged for home.

Becky and Morgan belonged in these conversations with Lori and me. There were explanations to hear and questions to sort out. I could bring my experience as a systems analyst and my habit of putting things into words. Neither gave me a complete view of what had happened or the right to speak over Lori.

She was an adult who knew the strain of her illness from the inside. I knew years of family history and the fear that accompanied it. We needed to bring those perspectives together while respecting her wish to make decisions and, eventually, her wish to end a discussion.

The final week contained more than advocacy. We spent time together. We met people who cared about her. We watched her make room for humor and conversation while recovering. Those moments helped us remember the life outside the hospital that everyone said they wanted her to return to.

I kept returning to a practical question: when we left this room, who would remain connected to the history and to the plan? A family can carry papers and memories home, but it also needs people who can respond when care becomes difficult.

That question would take us into the last conversations of the stay. We had come from Mountain View to stand beside our daughter. We hoped that, by the time we left, the knowledge gathered around her bed would travel with her too.



## Chapter 24

# The people working within the plan



Illustrative reconstruction

Some doctors worked hard to arrange medicines for home. They tried to find options and explain what could be done. We saw positive effort while we continued to question the larger decision about access.

I came to understand part of our frustration as a problem of continuity. A clinician joining the case might be working within a plan already established by others. That person might be trying sincerely to make the next part succeed without having been present for the original discussion or knowing the history that made the family anxious.

That possibility did not tell us exactly what any individual knew. It did help me see why an institution could contain brilliant people and still leave a family feeling that something important had not traveled with the patient.

We wanted the original reasoning available, especially when new people were expected to carry it forward. Without that connection, each conversation risked beginning with the conclusion rather than the path by which it had been reached.

I did not want our criticism to erase the work we were watching. The doctors trying to make medicines work were not abstractions called the system. They were people with responsibilities, trying to help a patient prepare to leave.

The nurses were people too. Their care could be technically important and personally reassuring. A kind exchange did not settle a question about access, but it could make the room easier to inhabit while the question remained.

This is why our final assessment would need more than a single number. An overall score could not explain the difference between appreciation for an individual's effort and dissatisfaction with a decision or a connection among teams.

The reassessment wheel proposal came from that difference. I was not trying to draw a list of bad people. I was trying to see where useful knowledge could fail to reach the point where it was needed, even when the people involved were dedicated to their work.

The more clearly I could describe that concern, the less I needed to turn a professional disagreement into a contest of character. We wanted a better explanation, a safer-feeling path for Lori, and a way for the family history to be considered without exhausting everyone who tried to tell it.

Palliative care came into the discussion as a question about comfort and quality of life. Lori said several people had suggested it might be appropriate for symptom support, and she did not understand why it seemed to be an obstacle. The family wanted that option, or another symptom-management approach, considered and explained. These notes do not establish that a consultation occurred or that any particular service had accepted responsibility.

Lori also recalled earlier discussion of fluids without a clear statement, as she remembered it, that the treatment itself was medically wrong. Her question was why options previously discussed were now being restricted and what would address the continuing symptoms in their place.

We worried that a new physician might inherit the prior team's conclusions through the chart without reconsidering the pattern. An earlier doctor's observation stayed with us: doctors can sometimes be wrong, and symptoms still deserve attention. That is a family recollection, not a verbatim quotation. We wanted consistent documentation to help the next clinician look again, including after discharge if the questions remained unanswered.

## Chapter 25

# The next generation



Illustrative reconstruction

The hospital's roots were a real thing to us. We had seen them in the historical displays, and now we could see something of its future in the people who volunteered their time.

Volunteers were there to spend time with Lori, show kindness, and help take her mind off her condition. We met a few of them. Our photographs preserve Lori in a public part of the hospital with young people wearing bright blue shirts, and then smiling with them for a picture. For that moment, she was part of a friendly group rather than the subject of another medical discussion.

I thought about the next generation of doctors, therapists, and nurses. I cannot assign each person a career from a photograph or say what each one will become. But I can describe the hope we felt in meeting them. They were giving time to another person, learning something of the hospital through being present in it.

That willingness matters. Expertise grows through education and practice. Kindness can begin with the simple decision to spend time with someone.

A university hospital teaches through far more than lectures. Patients and families meet its people in corridors, lounges, rooms, and places to get something to eat. The way a person is approached becomes part of what the institution means to them.

We wanted these volunteers in the book because our gratitude was specific. They helped Lori have a different kind of moment during a difficult admission. A conversation and a smile could make space for interests and companionship beyond the condition that had brought her here.

Our hope for the hospital remained great. We wanted the next generation to inherit the skill we had witnessed and the habit of listening we were asking the system to strengthen. A person's history should be something to learn from, with questions to examine carefully and explanations to share.

That hope connects the hospital's beginnings to its future. Community support helps a school grow. The school prepares people to care. Patients arrive carrying their own histories, and the encounter gives everyone something more to understand.

We had disagreements that this book would not hide. We also met people whose presence made us glad. The young volunteers belonged among them. They were part of the reason we could leave with concerns and still believe in what this hospital could become.



## Chapter 26

## Legend visits for the day



Legend came to visit for the day. He was Lori's service animal, part of the life that continued beyond the hospital's routines. Seeing him beside her brought some of that familiar world into the room.

The family photographs preserve their time together: the bedside visit, the courtyard, the paths outside, and a dog with an ordinary interest in the world around him. His presence also carried a history of trained service and the practical support Lori needed.

Legend is a long-haired German Shepherd. Before him, there was Zaya, the white King German Shepherd our family remembers so fondly. Their place in this story goes beyond companionship.

Lori works with animal behavior and service animals. The family describes Zaya and Legend as trained service-alert dogs who support her during episodes associated with her autonomic condition. Lori and the family report spells in which her blood pressure drops or her heart races, with concern about fainting. Their account of the dogs' role is to alert her and help support her safety.

Our family remembers Zaya moving through the University of Michigan's cardiovascular center and being welcomed for her training and behavior. In our telling, she was an early example of a professionally trained white King German Shepherd serving in those spaces. We also remember her being allowed into a post-operative area to support Lori. Those are family recollections; we have not established an institution-wide first or a documented historical ranking.

What stayed with us was the way her work was understood. Zaya had been professionally trained, and Lori brought her own knowledge of animal behavior to that relationship. The dog belonged beside the person she served, with a task and a purpose.

Legend continued that part of Lori's life. I have spoken of how dependable he has been in protecting her during her medical episodes. That trust is part of why we named him Legend. It expresses our family's experience of him, rather than a promise that any dog can predict or prevent every event.

The visiting therapy animals in our hospital interviews had a different role. Their visits could offer warmth and a welcome change in a patient's day. Lori's service dogs had tasks connected to her individual needs. Both stories belonged in the hospital account, and their roles deserved to be described clearly.

Outside, there was room for a walk. The hospital remained in the background while Lori and Legend spent time together. For a family whose conversations had become crowded with medicines, procedures, and plans, that ordinary time mattered.

This was the life we wanted the care plan to support: more days in which Lori could participate, with the people and the animals who belonged to her life. The story of Zaya and Legend will have more chapters as we continue writing her history.

## Before Legend: Zaya



Pencil interpretation of the family photograph: Lori with her first puppy, Zaya.

Lori's first puppy came into her life when she was nineteen, just before she graduated. She was weak and frail. But that little dog made her feel good. Her name was Zaya.

In the photograph, Lori holds the white puppy close to her face. She is smiling. When I look at it, I remember a young woman who was having a difficult time physically and still had room for the happiness a puppy could bring.

The later photographs show Zaya grown: the same white shepherd beside Lori as her life continued. The puppy picture is the beginning of that relationship, before the hospital memories and the service work we would come to associate with her.

There is a reason to remember that beginning here. Before we describe a trained task, there is a person and an animal learning each other. Before we explain what help was needed, there is the simple memory that this puppy made our daughter feel good.

## A Family Girl, a Family Woman



Pencil interpretation of a family photograph from Lori's younger years.

The main picture is friends and family. Lori grew up with brothers and sisters, grandpas and grandma, Mom and Dad, and the twins. The photographs hold those relationships together: people gathering, standing close, and making room for one another.

Other pictures come from hospital visits earlier in 2026, in a visiting room and in her hospital room. I remember her as heavier and healthier before she fell ill with major infections. I do not recall the full course well enough to reconstruct it here. Those earlier visits have their own history; they are not all scenes from the October stay.



Pencil interpretation of an earlier 2026 hospital visit with people close to Lori.

She was a family girl, and now she is a family woman. Zaya and Legend belong in that life, alongside the people who have loved her through the years. That is the life behind our questions about care at home: Lori's place among her people, with room to enjoy their company and to care about them too.

## Chapter 27

## She still knew how to entertain



Illustrative reconstruction

Lori never forgot her roots in entertainment and fun. Recovering from what our family experienced as major surgery, she still entertained friends and guests when she could. There was room for a joke, for something playful, for a familiar part of herself that the admission had not taken away.

The photographs tell that part of the story. Legend is beside the bed among the stuffed animals. Lori has a large blue puppet with a broad pink mouth and bright eyes. In one picture she holds it up; in another it leans toward Legend, turning the bedside into a small stage. The dog looks on, alert to whatever his person is doing.

The room has medical equipment, but it also has color, drawings, lights, and belongings. Lori was making room for herself in it. She could be a patient recovering from surgery and still be the person who wanted to bring a little fun to a visitor's day.

At night, the routine was different. As our family recalls it, she used oxygen and remained connected to monitors. During the stay, blood, iron, saline, and medicines for nausea were given through IV access. The exact timing and orders belong in the treatment record; what stayed with us was the contrast between those periods of support and the plan being discussed for home.

The doctors continued talking about discharge without access. Eventually that was how Lori left.

For us, the question was how the care supporting her in the hospital would translate into a workable life outside it. We understood that an inpatient treatment does not automatically become a home prescription. We still needed to understand what would take its place, how well that alternative was working, and who would respond if she could not keep the medicines down.

Her humor did not erase that concern. Neither did it make the laughter less real. These photographs preserve a woman who could entertain while she was healing, with Legend beside her and a puppet in her hands. That part of Lori belongs beside the symptoms and the treatment history. It is part of the life we wanted the plan to protect.



## Chapter 28

# Everyone agreed on home



Illustrative reconstruction

One of the conversations we described involved three doctors coming into Lori's room. Her response, as our family remembers it, was simple: "Yep, I'm fine." The plan was to send her home.

Everyone did agree that she should go home. Lori wanted it. The family wanted it. The team was arranging it. We appreciated the work being done toward that goal.

Her brief answer should stay beside the rest of her account. We had continued to describe vomiting and difficulty with medicines. Saying she was fine in that exchange did not, for us, mean that every symptom had resolved or that the medical history had become irrelevant.

It also should not be used to take her wish to leave away from her. Lori could want discharge while continuing to have symptoms and questions. Those things could exist together.

The three-doctor scene and the later conversation involving the male nurse administrator should not be folded into one invented meeting. Different conversations contributed different parts of the family's understanding.

We had reached a point where going home was both a shared goal and an unresolved practical question. Medicines could be prepared, belongings gathered, and discharge discussed while the family still wondered how the plan would work after the hospital.

We needed to know whom to contact, how the response would be reviewed, and what to do if Lori could not keep medicines down. We also wanted the knowledge accumulated before this stay connected to the people who would see her next.

Those questions did not make agreement impossible. They explained the limits of what we were agreeing to. We could accept the discharge plan as the next step without announcing that our concerns had been settled.

I wanted to be careful about the word fine. A father's worry can turn it into evidence that his daughter has given up. That may be unfair to her. Lori spoke for herself. We can record the words and her desire to leave without assigning a hidden reason to them.

What our family could say clearly was that we wanted her home and remained concerned about how her needs would be met there. That distinction would remain important during the final discussion, when the male nurse administrator helped create another opportunity to share the history.

The letter asked for answers that could work outside ordinary office hours. Who would help during evenings or weekends? How quickly could hydration or essential medicines be provided if Lori could not keep them down? What was the alternative if outpatient care failed? We wanted active ownership of those questions, with an explanation of what was known, what remained uncertain, and who was responsible for each part.



## Chapter 29

# The administrator brought him back



Illustrative reconstruction

The male nurse administrator brought the doctor back into Lori's room and encouraged him to listen to our history. That is the role we want recorded. He was not another doctor in a white coat, and the description head nurse did not express the role as clearly as we later clarified it.

We appreciated his effort. He helped create an opportunity for a conversation we had wanted to have.

Lori, Becky, Morgan, and I were there. We were able to explain nearly forty years of care and discuss the personal reassessment wheel alongside the hospital's assessment. We spoke about childhood care, the children's hospitals, the earlier physicians, and the outside relationships that had continued into adult life.

The doctor listened. It would be inaccurate to leave that out because we were disappointed by the outcome. The difficulty was that, after listening, his recommendation remained unchanged. We did not feel he had reconciled the history with the plan for Lori to leave without access.

He returned to the assessment and described speaking with GI and cardiovascular specialists. The explanation centered on the absence of a willing IV prescriber and, therefore, the decision not to place a port.

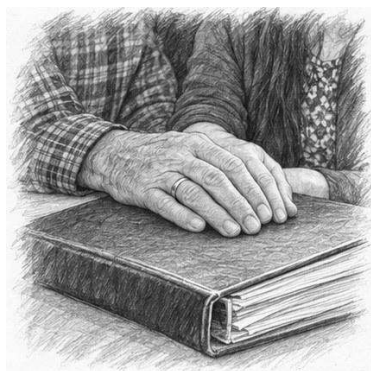
We described the long history of access and prescribed treatment. I chose not to bring the outside primary doctor further into the disagreement. We understood she had been involved in communications, but we did not have that full exchange in front of us.

The administrator's contribution and our dissatisfaction need to be told together. He helped the conversation happen. The doctor heard the account. We still did not understand how the account had changed, supported, or been outweighed in the final reasoning.

Listening and agreeing are not the same act. A doctor can listen and still recommend a different course. What we wanted was an explanation that showed where the earlier knowledge had entered the decision and why the plan remained appropriate despite the concerns we were describing.

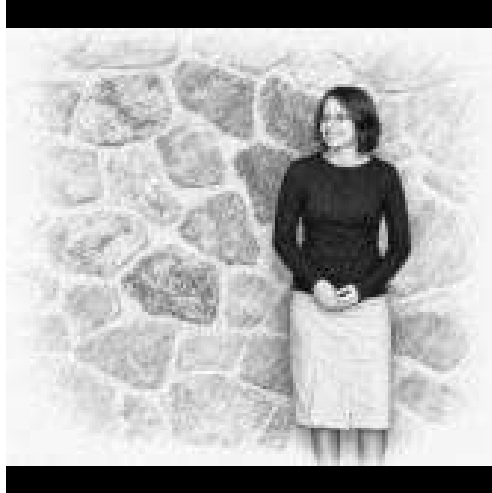
From our perspective, that explanation did not adequately connect the two wheels. I cannot conclude from that alone what review occurred outside the room. I can describe the gap that remained for the family when the conversation ended.

We had finally been able to share the history more fully. We were thankful for the administrator's help in making room for it. We remained disappointed that the plan, as we understood it, had not adapted in the way we hoped.



## Chapter 30

# The question that would follow us home



Illustrative reconstruction

What if the plan fails?

We asked what Lori should do if she could not keep the medicines down. The doctor said she could come back through the emergency room.

We heard the answer. It did not resolve our concern. From our family's observations, difficulty keeping medication down was already happening during the stay. We wanted to understand how that existing difficulty would be handled at home, not only where Lori could go if things became unmanageable.

Who would follow her? Who would review whether the plan was meeting her needs? What information would the next clinician receive? Those were the questions I carried alongside the answer about returning through the ER.

We did not bring up the GI doctor's absence. We did not discuss the 2008 study during this conversation. We listened to the explanation and agreed to proceed with discharge. The agreement was real, and so were the concerns that remained.

Lori had reached her limit with the discussion.

"Thank you. Please leave."

She said it again.

"Thank you. Please leave."

I thanked them too. The doctor and the male nurse administrator left the room. We continued to sit there together.

I was angry and disappointed. I felt that the history had not been given the influence it needed. Lori wanted to go. Both things could be true without turning her decision into mine or my reaction into a description of her emotions.

We had sought information about whether she could decline further conversation with this particular doctor. The general rights information we reviewed supported participation and refusal within the law, but did not create an immediate replacement clinician or settle the clinical questions. Our concern was that ending the debate should not prevent her from receiving essential discharge information.

I could say thank you and still disagree. I could appreciate the administrator's effort and still feel that the final explanation was inadequate. Those distinctions may sound easy on paper. In the room, with fatigue and worry accumulated over weeks, they took effort.

The conversation was finished. The need to understand Lori's care would continue beyond it.



## Chapter 31

## A room with great vibes



Illustrative reconstruction

During discharge, the surgeon who had removed the collection of blood from the area we called Big Bertha stopped by for one final evaluation.

Lori clarified the earlier wording as we worked through the account. The port had been removed. The troublesome chest area had involved a collection of blood. The surgeon explained that she had a hematoma and showed her how to pack the wound where the collection had been removed.

Those details helped us tell this part of the story more clearly. They should not be turned into a claim that the collection was a genetic tumor or that its cause had been proved by our observations. The explanation of a hematoma was part of what we recalled from the surgeon's visit.

Then he said something else. He told Lori that he always enjoyed stopping by her room during rounds because the room had such great vibes.

That was a warm thing to hear while we were preparing to leave.

The room had contained disappointment and repeated questions. It had also contained people being themselves. Lori had made connections with staff. The family had found ways to laugh and talk while waiting through difficult days.

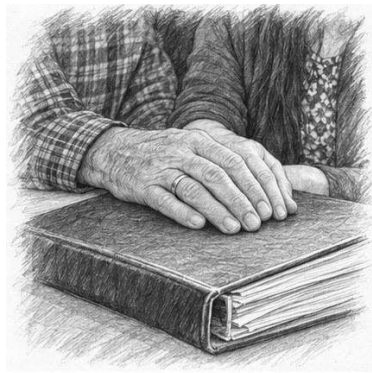
His comment did not settle the disagreement about access. It did not need to do that in order to matter. It recognized the person and the atmosphere around her rather than reducing the room to a list of problems.

I wanted it in the book because an account made only of conflict would leave out something we had experienced. The surgeon had returned, evaluated her, explained wound care, and offered a kind observation about being there. Those actions deserved to remain visible.

When a family is disappointed in one part of care, a positive moment can be mistaken for a contradiction. To us, it was part of the same hospital stay. We could be thankful for him and remain concerned about the plan ahead.

I will not invent a speech he did not give. His message, as we remember it, was that visiting Lori's room had been enjoyable because it had good vibes. That small, personal acknowledgment stayed with us.

It helped bring the story back to Lori. She had been a patient with a difficult course, but she had also been someone people enjoyed visiting. We wanted the book to leave room for both.



## Chapter 32

## Sarah and the man with the bags



Illustrative reconstruction

Sarah offered encouragement about the life ahead of Lori. As we remember it, she wanted Lori to know that she could move forward and have a good life. I am paraphrasing the message rather than presenting it as a recording.

After so much discussion of what might fail, the encouragement mattered. It recognized a future beyond the immediate room. We wanted that future too, with care that would allow Lori to take part in it.

Another friendship grew around a very ordinary task. A man came in to change the trash bags, and we enjoyed talking with him. He was kind, friendly, and looking forward to a dog he and his wife would welcome into their lives.

The conversation turned to the dog taking over the bed. We laughed about whether he would have anywhere left to sleep. In the middle of a hard stay, a small domestic joke made room for ordinary life.

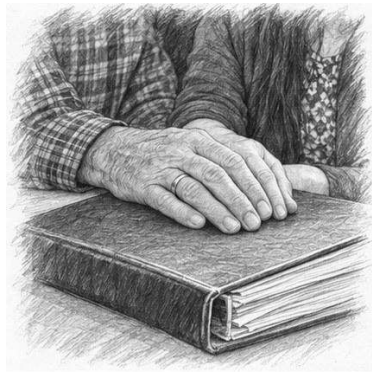
In the first spoken telling, pieces of his personal story were uncertain. I will not fill those gaps with a bereavement story or say the animal was a service dog when we had not established that. What I remember clearly is his warmth and the anticipation of welcoming the pet.

He was doing his work, and he was also a person with a home, a wife, and something he was looking forward to. Lori was a patient, and she was also a person capable of enjoying the conversation. For a little while, that was what connected them.

Legend belonged to Lori's life in a different way, as her service animal. The courtyard walk and being reunited with him were moments our family valued. We do not need to confuse one animal's role with another's to recognize the affection running through both stories.

These are not decorative scenes added to soften a difficult account. They are among the things we remember. If we ask that professionals hear the whole of Lori's history, we should also tell the whole of our experience with the people who worked around her.

Sarah's encouragement and the worker's humor would be part of our thanks. So would the doctors and nurses who tried to make the medicines and arrangements work. Their contributions belonged in the judgment we were about to make of the stay as a whole.



## Chapter 33

# Seven, Ten, and the Three We Kept



Illustrative reconstruction

We gave the overall hospital experience seven out of ten. I knew the number needed an explanation.

The many other doctors who helped Lori, the nurses, the staff, and the friendly man changing the bags received a ten from our family. We had seen brilliance, kindness, effort, and encouragement. We wanted those contributions recognized.

Our main doctor received a seven. I believed he felt he was doing the right thing. He never let down or gave up, as I put it, and I recognized that persistence. I still disagreed with how the final plan addressed the history we had brought into the room.

The scores were our family's way of expressing the experience. They were not official performance ratings or clinical measurements. The seven for the whole stay did not result from averaging individual scores. It described the unresolved weight of a decision that would follow Lori home.

We said we were keeping the other three points for ourselves. That was a metaphor for the history we still needed connected and the work we would have to do after leaving.

At the very end, the male nurse administrator had helped us share that history more fully. The doctor listened. What remained unresolved for us was how the earlier care and the current symptoms had been reconciled with the final recommendation.

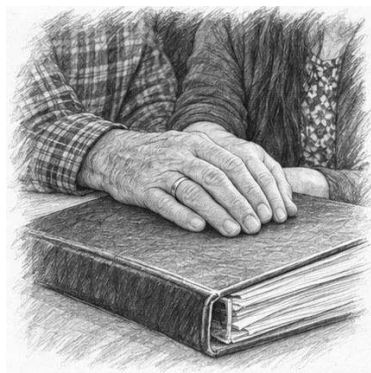
We had described childhood hospitals, physicians who kept searching, the long course of access and medications, and the outside primary doctor. We did not feel those connections had received sufficient weight in the explanation we heard. The plan remained for Lori to leave without vascular access.

We could recognize medical judgment without understanding enough about how that judgment applied to our daughter. We could accept discharge without feeling confident that every difficulty we feared had been addressed.

The three points therefore represented work ahead, not a punishment we could impose on a hospital. We needed to recover records, clarify the changes in treatment, reconnect with people who knew her history, and seek a plan we could feel confident was safe.

The other part of the score was gratitude. I did not want it lost in the disagreement. Many people had helped, and they deserved the ten we gave them in our family's telling.

"Seven for the experience as a whole. Ten for the many people who helped. Three points withheld for the history we still need connected to the plan."



## Chapter 34

# Pulling out of the garage



Illustrative reconstruction

We were heading out of the hospital, going down to the garage, preparing to pull away. The room that had held so much of our attention was becoming a place behind us.

We thanked our university friends at U of M. We regarded the hospital as one of the great medical institutions, and we wanted to acknowledge the care people had given our daughter. That appreciation did not require us to withdraw our questions.

I hoped the system would continue to improve. As a systems analyst, I kept thinking about the connections: how information moved, how responsibility changed, and how the history of one person remained available when the team or location changed.

The reassessment wheel proposal was our attempt to make that concern practical. It was still a concept. It would need careful development and evaluation before anyone could rely on it in care. But the need it tried to address had become concrete to our family.

I also thought about the portrait and recognition of A. Alfred Taubman. It had reminded me of the promise of a teaching hospital, where care, learning, research, and generosity can support one another.

I wondered whether Lori's complicated history could become an opportunity for further investigation, and whether work at other hospitals might help guide it. I did not know which funds could support a particular project. Seeing a donor's name did not tell me that money was available for Lori's questions or could be directed as I wished.

The question I wanted to preserve was about opportunity. When a patient brings a long, difficult history and an unresolved question about a genetic condition, is there a way to connect that experience with the people able to investigate it?

We wanted large hospitals to consider how reassessment works across their own departments and across outside networks. We also wanted Michigan's lawmakers to consider how patients participate and how their histories gain meaningful consideration. Those were requests for examination and improvement, not a conclusion that a law had been broken.

As we passed the university, we were carrying thanks and unfinished work. We did not need to choose only one to make the departure understandable. We were leaving a hospital where people had helped our daughter, with questions about the plan she would now have to live with.



## Chapter 35

# Life beyond the door



Illustrative reconstruction

We looked forward to sitting on the couch, relaxing, and taking everything in. As we had throughout the years, we would have a family conversation and decide how to move forward.

That was a hope for the next part of the day, not a clinical outcome I could report. The earlier illustrations of everyone settled at home were imagined scenes. They showed what we wanted: rest, connection, and enough support for Lori to live her own life.

We hoped that getting answers would not require months of repeating tests before anyone could determine what treatment and access she needed. We also hoped there might be effective options we had not yet explored. Our frustration did not give us the ability to know what the next assessment would find.

For now, we were looking toward Cleveland Clinic as another possibility. We were not announcing an appointment, acceptance, or a promised solution. We were naming a direction we hoped to explore while keeping the genetics question and the rest of her history connected.

Illness, human frailty, genetic disease, infection concerns, and disconnected information had all entered the story. I did not need to turn every professional into an enemy to explain why the family had been frightened.

Faith remained with us. We prayed for healing and looked to Jesus as the Great Physician. Prayer did not make the questions disappear. It was part of how we carried them while seeking practical care.

Lori's voice had to remain at the center. She could be grateful, angry, tired, hopeful, or finished with a conversation. She did not owe anyone a simple emotion to make the story easy to tell. My job as her father was to stand beside her and help when she wanted help.

The hospital stay had ended. The history had not. Neither had the possibility that future conversations could become clearer because we had written down what we experienced and what we still needed to understand.

We left with a seven for the overall experience and a ten for the many people who helped. We kept the other three as a reminder of the work ahead. Our gratitude and our unresolved concerns belonged in the same account.

We had put the goal into the Patient Relations letter: a successful discharge should give Lori a medically appropriate and realistic opportunity to stay home and have a life there. That remained our hope as we left. Listen. Reassess. Communicate. Care.

Every breath matters. Every voice matters. Quality of living matters.

Those words are how I want to end this chapter of our family's life. They are also why I wanted to begin the book with a person rather than a problem.

Meet Lori T.

Al Timberlane

Writer and Producer

IMAGINEVISION™ - Timberlane Entertainment Company LLC



# Chronology and Questions Carried Home

The focus: October 2026 at U of M. The family describes an admission expected to last two or three days that ultimately lasted twenty-nine. We do not infer an admission date from that duration or move earlier correspondence into October.

The history brought into the room: nearly forty years of care; NF1 since birth as described by the family; gastroparesis; earlier children's hospitals and physicians; approximately twenty years during which a port or other IV access generally formed part of treatment. Those periods are approximate, not a device-by-device record.

Earlier correspondence: a September 26 letter is marked 3:25:07 p.m. CDT. A call at approximately 3:29 p.m. reported that the PICC had already been removed. The call time is not its removal time. A follow-up letter acknowledged the changed situation. Those printed times need comparison with the clinical record for a full chronology.

The final week: Al and Becky arrived from Mountain View about six hours after their journey began, then stayed to help. The family account includes ongoing difficulty keeping medicines down, wound care, conversations about home, Legend's visit, volunteers, and Lori's humor.

At discharge: the male nurse administrator brought the doctor back to listen. He heard the history and maintained the recommendation for discharge without vascular access. The surgeon returned, explained the hematoma and packing, and offered the great-vibes comment. The family agreed to leave with gratitude and concerns still unresolved.

What remained to clarify: how the access and procedure findings related to the pain; what the cultures and operative reports established; how medication tolerance and response had been assessed; how outside prescribing changed; and who would review the home plan if it did not work for Lori.

Looking ahead: Cleveland Clinic was a possibility the family hoped to explore. The book does not announce an appointment, acceptance, recovery, or later medical outcome.

# Patient Participation and Research Notes

The legal questions in the story concern participation, communication, and continuity. Federal hospital rules address involvement in care planning and informed decisions, including the ability to request or refuse treatment. They also limit demands for treatment considered medically unnecessary or inappropriate. These rules provide context for our questions; they do not establish that a particular treatment was required or that a violation occurred. [R1]

Federal discharge-planning rules address patients' goals and treatment preferences, post-hospital needs, involvement of support people, reevaluation, and transfer of necessary information to follow-up providers. We wanted to understand how Lori's symptoms and earlier care connected to those arrangements. [R2]

Michigan Medicine's patient-rights information describes participation in care decisions, information about treatment, planning for after discharge, and ways to raise concerns. It also explains that requesting treatment does not mean demanding inappropriate services. [R3]

The practical question was how a meaningful explanation reaches the person who will live with the plan. Our family wanted to understand what had been reviewed, why a recommendation differed from earlier treatment, and who would remain responsible after discharge. An earlier imaginary courtroom argument did not answer those questions or establish liability.

For the genetics question, Damianos, Matkowskyj, and Camilleri's 2025 study discusses gut motility disorders, including gastroparesis, in people with documented NF1. It supports asking about a possible relationship in an individual patient's history. It does not establish the cause of Lori's symptoms, malabsorption, an intestinal injury, or the appropriate route for her medicines. [R4]

The reassessment wheel is a proposal for organizing those sources and responsibilities. A connection drawn on a screen is not proof that care has occurred. Any practical use would need accurate records, consent, privacy protections, clear ownership of updates, and clinical evaluation.

# Sources and Illustration Credits

Family materials: the earlier manuscript and correspondence; family corrections through October 16, 2026; Current Conversation Notes; the Patient Relations letter in the appendix; and Al Timberlane's supplied article, When the Wheel Breaks, Part Three of The Heart of Medicine Is the Patient, Good Morning Ozark American Journal™. Family photographs informed the sketches. Conversation notes are an informal summary, not a transcript. Clinical records are needed for a full chronology.

R1. 42 CFR 482.13, Hospital patient rights.

<https://www.law.cornell.edu/cfr/text/42/482.13>

R2. 42 CFR 482.43, Hospital discharge planning.

<https://www.law.cornell.edu/cfr/text/42/482.43>

R3. University of Michigan Health, Patient Rights & Responsibilities.

<https://www.uofmhealth.org/patients-visitors/patients/patient-rights-responsibilities>

R4. Damianos JA, Matkowskyj KA, Camilleri M. Enteric Neuromuscular Manifestations in Neurofibromatosis Type I. Neurogastroenterology & Motility. 2025;37(12):e70101. DOI: 10.1111/nmo.70101.

<https://pubmed.ncbi.nlm.nih.gov/40493756/>

R5. University of Michigan Medical School, From the Diag to the world: 175 years of U-M medical history.

<https://medschool.umich.edu/news-release/diag-world-175-years-u-m-medical-history>

R6. Library of Congress, Constitution Annotated: Due Process Generally (Fourteenth Amendment).

[https://constitution.congress.gov/browse/essay/amdt14-S1-3/ALDE\\_00013743/](https://constitution.congress.gov/browse/essay/amdt14-S1-3/ALDE_00013743/)

Illustrations: established AI-assisted pencil sketches and reconstructed scenes created for this family narrative, with proposed reassessment-wheel artwork. Clinical personnel are illustrative figures. No hospital endorsement is implied. Original family photographs informed selected sketches.

Sources checked during manuscript preparation, October 16-17, 2026. This edition contains thirty-five narrative chapters, followed by these reference notes.

Al Timberlane | Writer and Producer

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Every breath matters. Every voice matters. Quality of living matters.

# Family Advocacy Letter

The following letter was supplied by the family for this manuscript. Its language reflects the period when treatment and discharge arrangements were still under discussion. No date or delivery record was supplied with this copy. It is preserved as family advocacy correspondence, not as an independent verification of the procedural findings it describes. The incomplete page-footer fragment has been omitted; the letter's text and signatures are retained.

## PATIENT RELATIONS - FAMILY ADVOCACY LETTER

To: Patient Relations

Re: Lori Thomas - Reassessment, Continuity of Care, and a Safe, Workable Discharge Plan

Dear Patient Relations,

We are writing as the parents and family advocates of Lori Thomas concerning her current and prolonged hospitalization.

First, we want to make something very clear. This letter is not intended as an attack upon Lori's physicians, nurses, or hospital staff. Throughout this hospitalization, we have encountered many extraordinary nurses, physicians, and other professionals who have treated Lori with compassion, advocated for her, listened to her, and worked very hard on her behalf.

Our purpose is much simpler: we are Lori's parents, and our daughter's quality of life matters.

After watching this hospitalization unfold across numerous days, procedures, departments, specialists, nursing shifts, and changes in medical teams, we have become increasingly concerned about continuity of communication and timely reassessment.

Lori is a medically complicated patient. Her history cannot easily be understood from a single procedure, a single consultation, or a single day's progress note.

Yet the longer Lori has remained hospitalized, the more frequently the people caring for her have necessarily changed. Each transition creates another opportunity for important pieces of her history and the reasoning behind previous decisions to become disconnected from the current plan.

From our perspective, reassessment has therefore been bumpy at best.

We are not suggesting that every clinician should know every detail of Lori's history immediately. We understand how hospitals operate, that shifts change, specialists have different responsibilities, and procedural departments such as Interventional Radiology may see only one portion of a much larger case.

But that is precisely why we believe a medically complex patient requires a reliable system for someone to continue seeing the whole patient and the whole course of care.

### **Our Concern About Reassessment**

During this hospitalization, Lori experienced complications involving her vascular access, including problems associated with a PICC line, increasing pain and swelling, eventual removal of that line, continued difficulty obtaining reliable access, and a fluid collection requiring Interventional Radiology involvement.

There were periods when Lori and her family believed that repeated concerns were being communicated to IR without timely bedside reassessment.

When IR eventually performed an aspiration procedure, approximately 12 cc of dark, old-appearing, non-purulent fluid was reportedly obtained and sent for analysis. The procedural documentation further indicated that severe patient discomfort prevented aspiration of an additional smaller fluid compartment.

That experience itself became new information requiring reassessment.

Subsequent conversations have resulted in a plan to reschedule the procedure using a pain-management/anesthesia approach more appropriate to Lori's circumstances so that the remaining fluid can be addressed.

We appreciate that reassessment.

We also appreciate the physicians and nurses who listened when the first approach proved inadequate and who have worked to develop another plan.

Our concern is not that an initial plan sometimes fails. Medicine involves uncertainty, and individual patients respond differently.

Our concern is what happens after circumstances change.

### **Questions Raised by the Course of Care**

Does information reach the next team?

Does a failed or incomplete procedure cause someone to reconsider the plan?

When a patient's symptoms worsen, who sees the progression rather than each individual symptom?

When several specialties are involved, who is responsible for seeing the entire patient?

Those questions have repeatedly arisen during Lori's hospitalization.

### **Lori Has Remained Cooperative**

Lori has been remarkably patient, kind, and courteous throughout an exhausting hospitalization.

She has repeatedly demonstrated a willingness to consider alternatives.

When different medications have been proposed, she has been willing to try them. When the medical team discussed transitioning her pain medication, she expressed willingness to cooperate while asking that there also be an appropriate plan for significant breakthrough pain.

When concerns arose regarding sedation for an IR procedure, Lori did not simply refuse treatment. She explained her previous experiences and concerns, listened to the physician, discussed available options, and ultimately consented to an attempted procedure after a plan was developed that she believed she could try.

That procedure unfortunately caused substantial discomfort and could not completely accomplish its objective.

Again, Lori continued working with the medical team.

She is not asking to dictate her medical treatment. She is asking to be heard.

### **Twenty Years of Vascular-Access History**

One of our most significant concerns now involves discharge planning.

According to Lori and our family's history, for approximately twenty years Lori has depended upon some form of long-term IV access, including ports and/or PICC lines, as part of managing her complicated medical needs.

To our recollection, she has not ordinarily been discharged home without appropriate access during this period.

We ask that the hospital verify that history through Lori's medical records and consider why long-term access became part of her treatment in the first place.

We understand completely that a twenty-year history does not automatically mean that the same treatment must continue forever.

Medicine changes. Lori's circumstances change. Risks change.

If her physicians now believe that a port or PICC creates risks that outweigh its benefits, Lori and her family are prepared to listen to that medical reasoning.

But removing something that has played a significant role in keeping Lori functioning outside the hospital for many years creates another responsibility:

What replaces it?

### **Lori's Life Is Outside the Hospital**

This is where the issue becomes much larger than vascular access. It becomes a question of quality of life.

Lori has spent an extraordinary amount of time hospitalized, particularly during this past year.

But Lori's life is not the hospital.

Her life is at home. Her life is with family and friends. Her life is in her community, caring about other people and participating in the world around her.

There are times when Lori reports that she cannot keep adequate fluids or essential medications down. She knows the symptoms she experiences when she becomes dehydrated. Historically, vascular access has provided a means of addressing some of those situations without every episode necessarily becoming another prolonged hospitalization.

If the present recommendation is that Lori should return home without a port, PICC, or other appropriate access, then we respectfully ask the medical team to explain the complete alternative.

### **Questions That Need a Workable Answer Before Discharge**

How will Lori receive necessary hydration when she cannot maintain it orally?

How will essential medications be administered when she cannot keep them down?

Who does Lori contact when this happens?

How quickly can treatment be provided?

What happens during evenings, weekends, or other times when routine outpatient services may not be readily available?

What is the backup plan if the first approach fails?

How does this plan help Lori remain safely at home rather than repeatedly returning to the hospital?

We are not demanding a particular medical device.

We are asking for a workable plan for Lori's actual life.

### **A Reasonable Time for Resolution**

We also believe these questions need to be resolved within a reasonable period of time.

Lori cannot remain indefinitely between teams while fundamental questions concerning the remaining fluid collection, infection treatment, vascular access, pain management, and eventual discharge remain unresolved.

We recognize that complicated medicine takes time. Cultures take time. Consultations take time. Procedures sometimes have to be rescheduled. Physicians need time to review records and communicate with one another.

We are not asking anyone to rush a medical decision.

We are asking that the hospital ensure there is active ownership of the decision-making process so that necessary decisions continue moving forward.

Someone needs to be able to tell Lori:

This is what we know.

This is what we are still determining.

This is who is responsible for each part.

This is what needs to happen before you can safely leave.

And this is how we intend to help you live safely once you are home.

### **What We Are Asking Patient Relations to Help Accomplish**

We respectfully ask Patient Relations to help ensure that Lori's case receives coordinated review across the appropriate medical teams and that there is clear responsibility for her overall plan of care.

We ask that her long-term vascular-access history be reviewed before a final discharge decision is made.

We ask that the outcome and limitations of the recent IR procedure become part of the planning for the rescheduled procedure.

We ask that communication between the primary medical team, Interventional Radiology, Infectious Disease, vascular-access professionals, nursing, pain-management professionals when appropriate, and the physicians familiar with Lori's history be sufficiently coordinated that each service is not operating from only one portion of the story.

And before Lori is discharged, we ask for a clear, realistic and medically appropriate home-care plan addressing hydration, essential medications, vascular access if clinically appropriate, warning signs, whom Lori should contact when problems develop, and what the backup plan will be if outpatient management fails.

### **Our Perspective as Parents**

We recognize the limitations of our perspective.

We are not physicians. We do not see every clinical discussion occurring behind the scenes, and we do not possess all of the information available to Lori's medical team.

But we have something different.

We have been watching our daughter's story continuously.

While physicians, nurses, departments, and shifts necessarily change, Lori remains the same patient, and we remain her parents.

From that broader perspective, we can sometimes see where one part of the story appears disconnected from another.

We have described this within our family as taking a wide-angle or cinematic view of Lori's care - not because we believe we know more than her physicians, but because we are watching the entire sequence rather than one individual scene.

We respectfully ask the hospital to do the same.

Please help ensure that someone continues to see the entire patient.

Please continue to listen when Lori tells you what she is experiencing.

Please reassess when circumstances change.

Please help the different teams communicate.

And please do not measure a successful discharge simply by whether Lori can leave the hospital.

A successful discharge should give Lori a medically appropriate and realistic opportunity to stay home and have a life there.

We remain deeply appreciative of the nurses, physicians, and other professionals who have cared for our daughter with compassion. Some have gone well beyond what we could reasonably have expected, and we want that reflected in this record as clearly as our concerns.

Our goal is not confrontation.

Our goal is Lori.

Listen. Reassess. Communicate. Care.

Respectfully,

Alva D. Thomas

Father and Family Advocate

Rebecca S. Thomas

Mother and Family Advocate

On behalf of Lori Thomas