Texas Association for Home Care & Hospice
Leading ★ Advancing ★ Advocating

57th Annual Meeting

Wednesday, September 2, 2026
Crockett CD Room
11:15am-12:15pm

1b. When the Expert Becomes the Daughter: Leadership Lessons from a Family's Hospice Journey

(How a "real life" personal experience reminds us of our "why"- and impacts compliance and quality!)

Presented by:

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PROVIDER INSIGHTS

WHEN THE EXPERT BECAME THE DAUGHTER

Lessons from my father's hospice journey on quality, compliance, and the heart of the mission

Annette Lee
RN, MS, HCS-D, COS-C · Founder & CEO, Provider Insights

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WHO IS STANDING IN FRONT OF YOU

Two lenses on the same sixteen days

The consultant

30+ years in home health & hospice compliance, clinical education, and reimbursement

Founder & CEO of Provider Insights, serving agencies across the country

I teach quality measures, surveys, and the Conditions of Participation for a living

The daughter

On April 30, my father elected the hospice benefit.

For sixteen days I watched our profession from the other side of the bed.

What I saw made me a better consultant — and reminded me why the rules exist.

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THE THESIS OF THIS HOUR

> *Families don't remember regulations.*
> *They remember how you made them feel.*

But here is the twist I want to prove today: every feeling my family will carry forever was built on a foundation of compliance done right.

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WHERE WE'RE GOING

Our path through sixteen days

The decision	Choosing a hospice — and integrity at the front door
The admission	First impressions, timeliness, and the whole team
Sixteen days	The story — from election to final breath
Anticipation as a condition	Assessment, the IDG, and advocacy across settings
Technology serving compassion	Voyage, HVLDL, SIA, HOPE, and the HCI
The whole family is the patient	Education, honoring service, and bereavement
What families remember is what CMS measures	CAHPS Hospice and the business case for the mission

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PART I

It Was Time: Choosing a Hospice

Like many families, we interviewed more than one hospice. Both looked capable. One stood apart within hours — and taught me what integrity at the front door really means.

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THE FIRST IMPRESSION

A liaison who never lost the clinician's heart

Within hours of our call, a liaison named Ryan sat down with our family. A nurse by background, he had never lost the heart of a clinician. He never overwhelmed us — he gave us what we needed, when we needed it, and gave my mother room to feel what she was feeling.

COMPLIANCE, NOT JUST KINDNESS

Electing hospice is a regulated moment of informed consent — and an emotional threshold for a family. Ryan recognized it was time, but he supported the decision instead of selling it. Done this way, informed consent doesn't feel like signing a form. It feels like being cared for.

- §418.24 Election & informed consent
- §418.52 Patient rights & dignity

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WHAT A COMPLIANT ADMISSION SOUNDS LIKE

Integrity at the front door

NOT THIS

A sales pitch. Steering a family toward an admission regardless of whether you are truly the right fit for their needs.

BUT THIS

Ryan openly discussed situations where another hospice — one with an inpatient unit — might serve us better. He was willing to help even if we chose someone else.

§418.24 Election · §418.52 Rights & informed choice

Admitting only the patients you can truly serve is not lost revenue. It is the integrity every survey — and every family — is looking for.

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ELIGIBILITY IN THE REAL WORLD

Compassion paired with compliance

AT THE BEDSIDE

My father hadn't been hospitalized in years — a tribute to my mother's caregiving, but it left gaps in the records we usually lean on for eligibility. Ryan never waved the documentation away. He reassured us we had time to gather it, while recognizing what was clinically obvious.

IN THE REGULATION

§418.22 Certification of terminal illness

§418.22(b)(3) Physician narrative

§418.25 Admission to hospice care

Eligibility must be supported by clinical documentation and the certifying physician's narrative. But the regulation expects clinical judgment applied to the whole picture — not a particular hospitalization history. A skilled liaison closes the documentation gap without ever making the family feel like a case that has to be proven.

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PART II

The Admission That Set the Tone

Hospices never get a second chance at a first impression. By the time my father reached his new room, the hospice was already there.

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BEFORE THE FIRST NIGHT

The team arrived before he did

AT THE BEDSIDE

My father was moving into a facility for dementia and complex medical needs. Before he crossed the threshold, the hospice had delivered and arranged his equipment — down to an overbed table I hadn't thought to ask for. It was a small thing. Looking back, it was not. Someone had already been caring for him.

IN THE REGULATION

- §418.56 Plan of care & coordination
- §418.54(a) Initial assessment ≤ 48 hrs
- §418.202 Covered services & DME

Equipment doesn't arrive early by accident. The initial assessment and the plan of care drive what a patient needs and when — and the benefit covers the supplies and durable medical equipment to meet those needs. Anticipatory delivery is simply the plan of care reaching the bedside before the patient does.

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THE FIRST 72 HOURS

The whole team — without delay

THE TEAM, IN ORDER

Admitting RN
Comprehensive assessment — warm, yet thorough

Social worker & chaplain
Same day and the next

Hospice aides
Within the first days

Music & massage therapy
Within the first week — Dad loved both

IN THE REGULATION

- §418.56 IDG establishes & coordinates care
- §418.54 Comprehensive assessment ≤ 5 days
- §418.64 Core services provided by the hospice
- §418.78 Trained volunteer program

The speed and breadth weren't luck. The CoPs require the interdisciplinary group to establish and coordinate care, the comprehensive assessment within five days, and core services delivered by the hospice. Music and massage therapy show a plan of care built around the whole person — not just a diagnosis.

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FAMILY AS THE UNIT OF CARE — FROM DAY ONE

They anticipated what we needed before we asked

A TEXT ON THE DAY OF ADMISSION

- What to expect in the dying process
- Support services and community help
- Virtual and in-person support groups

WHY IT COUNTS

- §418.52 Rights · §418.56 Education in the POC

Two CAHPS Hospice domains — Getting Timely Help and Communication with Family — ask families about exactly this. Proactive education isn't extra. It is what the national survey measures, and what the plan of care must document.

They weren't waiting for us to ask for help. They anticipated what we would need before we knew to need it.

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PART III

Sixteen Days

Elected hospice April 30. Died peacefully May 16. Sixteen days that redefined what I call extraordinary care.

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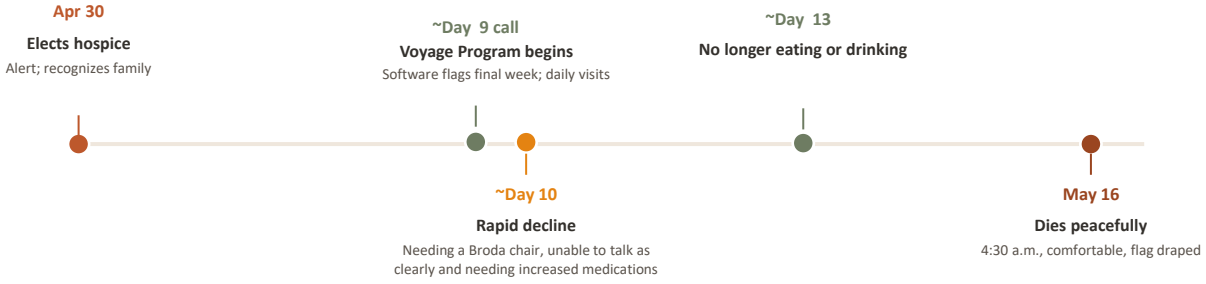
THE ARC OF THE JOURNEY

From election to final breath



16 days total — the entire relationship between this hospice and my family fit inside two weeks and two days.

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THE CHANGE NONE OF US EXPECTED

A decline measured in days, not months

At admission

He could still interact. He recognized the people around him. It felt like we had time.

Within two weeks

He had become non-responsive. Every day looked different from the one before. We did not see it coming.

The clinical reality of hospice: the patient in front of you today is often not the patient you assessed at admission.

WHAT EXCELLENCE LOOKED LIKE

Always one step ahead — never merely reacting

Every change

met with a reassessment

Every symptom

met with a thoughtful intervention

Every challenge

met with calm confidence

There were twists and turns — but I never once felt that anyone was simply reacting. They were anticipating.

As a consultant, I noticed the clinical excellence.

As a daughter, I noticed something more important:

“I never had to wonder whether someone was watching over my dad.”

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PART IV

Anticipation Is Not an Accident. It Is a Condition of Participation.

The feeling that someone was always one step ahead has a regulatory name: ongoing assessment, interdisciplinary planning, and coordination.

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EVERY CHANGE MET WITH A REASSESSMENT

The comprehensive assessment is a living document

AT THE BEDSIDE

As his condition shifted, the team reassessed — not on a fixed schedule, but whenever something changed. New symptom, new plan. The care always matched the patient in the bed that day, not the patient admitted two weeks earlier.

IN THE REGULATION

§418.54 Comprehensive assessment

§418.54(d) Update of assessment

The comprehensive assessment must be updated by the interdisciplinary group as frequently as the patient's condition requires — and no less frequently than every 15 days. “As the condition requires” is the operative phrase: a fast decline demands more frequent reassessment, not less. Continuous assessment is not above-and-beyond care. It is the baseline the regulation defines.

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THE TEAM I NEVER FULLY SAW

Behind one calm nurse stood an entire team

IDG

§418.56 Interdisciplinary group & plan of care

One coordinated plan of care — reviewed and revised by the group as his needs changed.

- **Physician / Medical Director**
- **Registered Nurse**
- **Medical Social Worker**
- **Spiritual & bereavement counsel**
- **Hospice aide**

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ADVOCACY — EVEN WHEN IT WAS UNCOMFORTABLE

Retaining responsibility across every setting

AT THE BEDSIDE

My father was in a nursing facility. The hospice advocated relentlessly for the care he deserved — sometimes respectfully challenging the facility's medical director to be sure he received the medications and interventions he truly needed. They never lost sight of the goal: not just treating symptoms, but protecting comfort and dignity.

IN THE REGULATION

§418.112 Hospice care in a SNF / NF

§418.52 Patient rights

When a hospice patient resides in a facility, the hospice retains professional management responsibility for the plan of care. That coordination duty is not a courtesy — it is the regulation. Advocacy with a facility's medical staff is the hospice fulfilling its obligation, not overstepping it. The written agreement and care coordination exist precisely so no one falls through the gap between two providers.

WHY IT FELT SEAMLESS

Coordination is a duty, not a nicety

1. Assess
Detect the change early, at the bedside

→

2. Communicate
Bring it to the IDG and the attending

→

3. Revise
Update the plan of care to match

→

4. Deliver
Right intervention, right time, one team

§418.56(e) Coordination of services across all settings & disciplines

The family sees a smooth surface. The regulation describes the machinery underneath.

WHAT THE EVIDENCE SAYS

The case for anticipatory care

Proactive symptom management

Anticipating and pre-empting symptoms — rather than reacting to crises — is associated with better comfort and fewer avoidable escalations near the end of life.

Families judge the whole experience

In landmark work on family perceptions of end-of-life care (Teno et al., JAMA 2004), families rated care by whether needs were anticipated and met, not by task completion.

Setting matters

Research consistently finds coordination gaps are greatest across care settings — exactly where anticipatory hospice oversight adds the most value.

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MAKE IT OPERATIONAL

What 'anticipation' requires of an agency

- Reassessment triggers tied to clinical change, not just the calendar
- IDG communication fast enough to revise the plan within hours
- Staff trained and empowered to advocate across facility settings
- Documentation that shows the assessment tracked the trajectory
- A coordinator who truly owns the plan of care
- Leadership that treats §418.54 frequency as a floor, not a target

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PART V

The Voyage Program: Technology Serving Compassion

A week before he died, a nurse called. Their software had seen what our hearts were not ready to see.

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ABOUT A WEEK BEFORE HE PASSED

"Do you have time to talk?"

The nurse explained, gently, that their clinical software had identified subtle trends suggesting my father was entering his final week of life. Because of those changes, they were initiating what they called the Voyage Program — increasing nursing visits to daily.

> *I remember thinking, that can't be right. He had only been on hospice for about a week. Surely we had more time. We didn't. Exactly one week later, my father died peacefully.*

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THE PRINCIPLE

Technology serving compassion — not replacing it

NOT THIS

Artificial intelligence replacing clinical judgment — a number deciding a person's care.

BUT THIS

Technology recognizing subtle changes, then handing an experienced clinician the chance to prepare a family before a crisis.

To me, that is what healthcare should look like: technology serving compassion.

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THE DAILY VISITS HAVE A NAME AT CMS

Hospice Visits in the Last Days of Life (HVLDL)

2 of 3

in-person visits on at least two of the patient's final three days of life

- A claims-based quality measure in the Hospice Quality Reporting Program (CBE #3645).
- Counts in-person visits by a registered nurse or medical social worker in the last three days of life.
- CMS chose it because the final days carry the highest symptom burden — and because consistent visits are perceived by families as better care.
- It aligns with the Service Intensity Add-on (SIA), which pays hospices to send RNs and MSWs when death is near.
- Publicly reported on Care Compare — the score families and referral sources can see.

The Voyage Program's daily visits were compassion. They are also, precisely, what this measure rewards.

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DATA-DRIVEN CARE IS REQUIRED CARE

From bedside signal to agency quality

QAPI

§418.58

Your program must use data to monitor and improve care. The software that flagged my father's decline is QAPI made visible at the bedside.

HOPE

Oct 1, 2025

The Hospice Outcomes & Patient Evaluation tool replaced the HIS — a real-time assessment designed to capture changes as they happen, not just at admission and discharge.

HCI

Care Index

The Hospice Care Index bundles ten claims-based indicators of care throughout the stay — a composite check on whether patterns like visit frequency hold up.

WHY THE FINAL DAYS CARRY THE MOST WEIGHT

The last days concentrate the hardest symptoms — and the memories that last longest.

- CMS built HVLDL specifically because the actively-dying period brings the most severe symptoms and the greatest need for skilled presence.
- Families consistently perceive frequent, in-person visits at the very end as higher-quality care.
- Increased visit intensity near death is the behavior both the quality measure and the payment policy are designed to encourage.

PART VI

The Whole Family Is the Patient

The very best hospice care wraps itself around an entire family — and the regulation says so out loud.

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THE DAY BEFORE HE DIED

Presence you can feel — never a visit on a schedule

AT THE BEDSIDE

His nurse spent more than two hours at his bedside. She assessed every change, quietly explaining what she saw while keeping him completely comfortable. Before leaving, she arranged for another nurse to return that evening. There was never a sense of rushing — never the feeling that we were just another visit.

IN THE REGULATION

§418.64(b) Nursing services

§418.56 Coordination

Core nursing services must meet the patient's needs — and near the end of life those needs are continuous. Arranging the evening nurse before leaving is coordination of care in action. “Unhurried” is not a luxury add-on; it is what it looks like when staffing, assessment, and coordination are resourced to match acuity.

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THE THINGS NO QUALITY MEASURE FULLY CAPTURES

The basket, the gift, the chocolate

A basket of snacks

so family wouldn't have to leave his bedside

A thoughtful gift

practical essentials — and yes, chocolate

Someone thinking of us

not just of our father

Medicare Benefit Policy Manual, Ch. 9 ·10

"The hospice philosophy considers the patient and family as a single unit of care." The little things aren't extra. They are care delivered to the actual unit the benefit defines.

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"WHEN THE TIME COMES"

Education that turned fear into understanding

AT THE BEDSIDE

The hospice gave us a booklet written in language my mother and sister could understand. It explained the physical signs of dying without creating fear. I watched them hold it, look at him, look back at the page — and finally understand what was happening. Knowledge replaced fear. Understanding replaced uncertainty.

IN THE REGULATION

§418.52(c) Right to be informed

§418.56(c) Education in the plan of care

§418.64(c) Counseling & support

Patient and family education and counseling are required elements of the plan of care and of the counseling core service. Teaching families the signs of the dying process is not optional kindness — it is a regulated service that the plan of care must reflect and the IDG must provide.

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WHY THE BOOKLET MATTERED SO MUCH

Educated families suffer less — and grieve better

BEFORE

- Wondering what each change meant
- Fear of the unknown at every breath
- Energy spent on uncertainty

AFTER

- Recognizing the signs, prepared for them
- Presence instead of panic
- Time spent simply being with Dad

Evidence links caregiver preparation to lower anxiety during care and healthier bereavement afterward.

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ONE FINAL ACT OF HONOR

They draped an American flag over my father before he left the room.

He was a veteran. They had honored his service throughout his care, and honored him one last time as he left. To them he was never a diagnosis or a room number — he was a husband, a father, a grandfather, a veteran, a man whose life mattered.

We Honor Veterans (NHPCO + VA) · §418.52 dignity & respect

A structured, national program — pinning ceremonies, veteran-specific training, and recognition — not an improvised gesture.

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4:30 A.M., MAY 16 — AND AFTER

The care did not end when his heart did

AT THE BEDSIDE

The nurse arrived quickly and sat quietly with us. When we needed to be alone, she gave us space. When we needed presence, she returned. No urgency. No pressure. Only kindness. Long after the medications are forgotten, this is what we will remember.

IN THE REGULATION

§418.64(d) Bereavement counseling

§418.56 Plan of care

Bereavement is a required core service. The hospice must have an organized program, reflected in a bereavement plan of care, that provides support to the family for up to 13 months after the death. The nurse sitting with us was the on-ramp to a service the regulation guarantees — grief support does not stop at the moment of death.

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THE BRIDGE

The small things were the big things

The moments my family remembers most were never the medication changes or the documentation. They were the nurse who stayed longer than she had to. The therapist who brought joy. The booklet. The phone calls. The snacks. The flag.

Here is the part that should change how we lead:

Every one of those “small things” is something CMS now asks families about directly — and reports publicly. What we dismiss as the soft stuff is precisely what the national quality survey was built to measure.

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PART VII

What Families Remember Is What CMS Measures

The CAHPS Hospice Survey asks grieving families about the very moments this story is made of.

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THE SURVEY SENT TO FAMILIES AFTER EVERY DEATH

CAHPS Hospice measures the experience of care

- Communication with Family
- Getting Timely Help
- Treating Patient with Respect
- Emotional & Spiritual Support
- Help for Pain & Symptoms
- Care Preferences
- Training Family to Care
- Rating & Willing to Recommend

Administered to the primary caregiver after the patient's death · publicly reported on Care Compare · required for full payment.

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THE MAPPING

Each moment my family remembers is a domain CMS scores

The nurse who stayed two hours, unhurried	→ **Getting Timely Help · Respect**
The phone call preparing us for the final week	→ **Communication with Family**
Daily visits and controlled symptoms	→ **Help for Pain & Symptoms**
“When the Time Comes” booklet	→ **Training Family to Care**
The flag, the dignity, honoring the veteran	→ **Care Preferences · Respect**
Sitting with us at the moment of death	→ **Emotional & Spiritual Support**
Would we recommend them? Without hesitation.	→ **Willing to Recommend**

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FOR THE OWNERS AND LEADERS IN THE ROOM

The mission and the margin point the same way

Publicly reported

CAHPS and claims measures appear on Care Compare, where families and referral partners compare you to competitors.

Tied to payment

Failing to report CAHPS data risks a reduction to your annual payment update. Quality reporting is a condition of full reimbursement.

Census & reputation

Willingness to recommend is the referral engine. Families who felt held send you the next family.

Staff retention

Clinicians stay where they're resourced to give the care in this story. Mission-fit care is workforce strategy.

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THE EVIDENCE BASE

Family experience is a real quality signal

It was validated on purpose

CMS contracted RAND to design CAHPS Hospice with input from families, clinicians, and researchers — the domains reflect what matters to real caregivers.

Setting shifts experience

Research (Teno and others) shows families report different experiences across home, facility, and hospital — making coordination across settings a measurable differentiator.

Experience is not “soft”

Caregiver-reported experience correlates with the domains that define good end-of-life care: communication, symptom relief, respect, and support.

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THE REFRAME TO CARRY HOME

Compliance is the floor. Mission is the ceiling.

The Conditions of Participation are not the enemy of compassion — they are its blueprint. Meet them, and you have the floor beneath a dying man's dignity. Reach past them, and you get sixteen days a family will bless for the rest of their lives.

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IN CLOSING

Bringing It Home

Take this back to your team on Monday. What would my father's family have felt in your agency?

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THE LEADERSHIP CHALLENGE

Take this to your team on Monday

Ask not only **"Are we providing excellent care?"** but also **"How will this family remember us?"**

- ✓ Review your admission process for timeliness
- ✓ Ensure competency in every team member
- ✓ Audit interdisciplinary involvement in the first 72 hours
- ✓ Evaluate your caregiver and family education
- ✓ Assess your anticipatory care planning
- ✓ Leverage data and technology to provide better care

Then ask every employee: ***"How do we make families feel?"***

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IF YOU REMEMBER NOTHING ELSE

Five things to carry with you

1. Anticipation is a condition of participation	Continuous assessment and coordination are the regulation, not extra effort.
2. Let technology serve compassion	Tools should surface signal and return judgment to the clinician.
3. Show up in the final days	HVLDL and the SIA reward the visits families remember most.
4. The family is the unit of care	Education, honor, and bereavement are core services — document them.
5. What they remember is what CMS measures	CAHPS Hospice turns 'how you made them feel' into public quality data.

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PROVIDER INSIGHTS

Thank you, Dad.

Questions

Long after the medications are forgotten and the documentation is filed away, the small things are what families remember. Let's make sure they're what our agencies are built to deliver.

Annette Lee, RN, MS, HCS-D, COS-C
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