

Designing Custom Support Pathways for Family Caregivers

A Community Review and Clinical Study Blueprint

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The Myth of the 'Average' Stroke

Why a single total hospital score fails family carepartners

The Standard Hospital Practice

- Hospitals compress a stroke survivor's condition into one global total number.
- This single total number is used to judge safety and write generic discharge guides.
- Flaw: An identical total score mathematically hides completely distinct home care realities.

The Real-World Caregiver Workload

- Physical Support Profile: Severe arm and leg weakness requires heavy biomechanical workloads, transfer training, and continuous fall prevention.
- Cognitive & Planning Profile: Changes to speech or swallowing require meal texturing, aspiration tracking, and intense coordination.
- The Goal: Prove the hospital must map individual symptoms to provide custom family care plans.

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What I Am Proposing: A Study, Not an Experiment

[Reassurance on clinical boundaries and standard workflows](#)

100% Non-Interventional Study: This project is purely an observation of how families naturally experience the transition out of the hospital.

Stroke Survivors Will NOT Participate in Active Trials: No testing of experimental drugs, physical therapies, apps, or medical devices.

Unchanged Hospital Routines: Standard medical management and discharge timelines remain completely unaffected by this research.

A One-Time Look at Patterns: We are simply capturing the baseline reality through a short questionnaire to learn how to build future care pathways.

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Understanding the Science: What is a Correlation?

[How we analyze real-world patterns without running experiments](#)

Defining Correlation in Plain Language: A statistical check to see how closely two or more real-world variables move or shift together.

No Cause-and-Effect Claims: We are not forcing changes to see what happens. We are measuring whether existing factors naturally pattern confidence.

The Three Building Blocks We Are Mapping:

- **Stroke Symptoms:** How do specific clinical chart markers relate to family preparedness?
- **Team Collaboration:** Does open communication with hospital staff link to higher confidence?
- **Background Factors:** How do living arrangements, income tiers, or advance directives tie into readiness?

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Our First Focus: Tracking Specific Stroke Symptoms

[Breaking down the medical chart into five continuous categories](#)

Instead of relying on a blended total score, our statistical models pull five distinct categories:

1. Consciousness & Alertness: Measuring orientation, baseline responsiveness, and basic cognitive presence.
2. Vision & Sight Fields: Tracking visual limits or blind spots that impact safety layout at home.
3. Speech & Language: Identifying communication barriers, clear comprehension, and expression limits.
4. Motor Strength & Movement: Summing left and right arm/leg function to isolate exact physical handling needs.
5. Sensation & Spatial Neglect: Capturing sensory loss or spatial unawareness that creates immediate home hazards.

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Our Second Focus: Healthcare Team Collaboration

[The exact questions we use to evaluate hospital communication](#)

Caregivers rate their experience with the Mount Sinai staff using a 0-to-4 scale (Never to Always):

- Tracking Technical Trust: 'The members of the healthcare team struck me as quite competent.'
- Protecting Dignity: 'Members of the healthcare team treated the patients with respect (tone of voice, addressing them).'
- Valuing Family Insight: 'Members of the healthcare team inquired about my knowledge of my family member's situation.'
- Sharing Authority: 'I was able to influence decisions that were made with regards to my family member's treatment.'
- Preparing the Exit: 'I was properly informed about the plans for my family member after they are discharged.'

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Measuring the Outcome: The Discharge Preparedness Scale

The core questions checking a caregiver's real-world readiness

Caregivers answer 25 specific questions using a 0-to-3 scale to rate their practical preparedness:

- Handling the Timeline: 'How much do you understand about the stroke survivor's expected recovery over the next 6 months?'
- Physical Management: 'How prepared are you to provide the stroke survivor assistance with personal care (bathing, moving around)?'
- Personal Health Boundaries: 'Do you think your own health problems will affect your ability to provide care?'
- Household Economics: 'Is there enough money available to pay for things not paid for by insurance (medications, equipment)?'
- Architectural Access: 'Will there be any accessibility problems for the stroke survivor getting around in the house (stairs, doorways)?'
- Emotional Grounding: 'How mentally prepared are you to be a caregiver?'

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The Hospital Workflow: Protecting Your Energy and Time

Step-by-step clinical floor mechanics across a target of 100 families

1. Clinical Screening: I review the Neuro ICU and Stroke Unit census daily. I never approach a family during active medical crises.
2. The Discharge Trigger: We only speak after a physician confirms medical stability and writes a formal pending discharge order.
3. Private Environment: The discussion takes place face-to-face inside your private inpatient room with the door closed.
4. Mobile Survey Tool: Caregivers complete a one-time, 15-minute questionnaire on a secure hospital tablet.
5. The Remote Pathway: If you are away from the hospital packing or working, I call to review the text and text you a secure link.

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Absolute Anonymity & Clinical Safety Nets

Ensuring data security and immediate support codes

- The Caregiver Lock: We never touch a stroke survivor's chart unless their caregiver explicitly reviews the project details and joins first.
- Total De-Identification: No names, medical record numbers, or addresses are ever written down or stored in the database.
- Coded Tracking Labels: Participants are filed under anonymous codes like 'Caregiver 42' and 'Stroke Survivor 42'.
- Complete Independence: Individual answers are saved on secure hospital software and never shared with the active bedside care team.
- Why a Patient Consent Waiver Exists: Acute strokes frequently cause sudden speech or clarity limits. Waiving explicit signed paperwork for survivors ensures severe stroke situations are represented, preventing a high-functioning study bias.

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Where I Need Your Guidance: Open Community Audit

Direct prompts for stakeholder critique and blueprint adjustments

Nothing is off-limits. Please critique our project blueprint across these core areas:

- Is a 15-to-20 minute survey a realistic ask during the chaotic window of a pending hospital discharge?
- Does the remote phone outreach and secure text link option sound like a genuinely flexible workaround or a stressful nuisance?
- **These tools ask about sensitive family structures, financial adequacy, and relationship conflict. Does that feel too intrusive?**
- We are offering a \$30 digital gift card as a thank-you token. Is this a respectful reflection of your time and effort?
- **Are there massive, critical pieces of your daily home reality that our questions are completely missing?**

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