



Family First: Prioritizing Caregivers in Hospital at Home

Rani E. Snyder, MPA | The John A. Hartford Foundation

Ian Strasfogel & Judith Norell | Former HaH caregiver and patient

Brittni Howard, MA | Icahn School of Medicine at Mount Sinai

Rita B. Choula, MA | AARP Public Policy Institute

Pamela Saenger, MD MPH | Yale New Haven Health



The
John A. Hartford
Foundation

Webinar
February 20, 2024



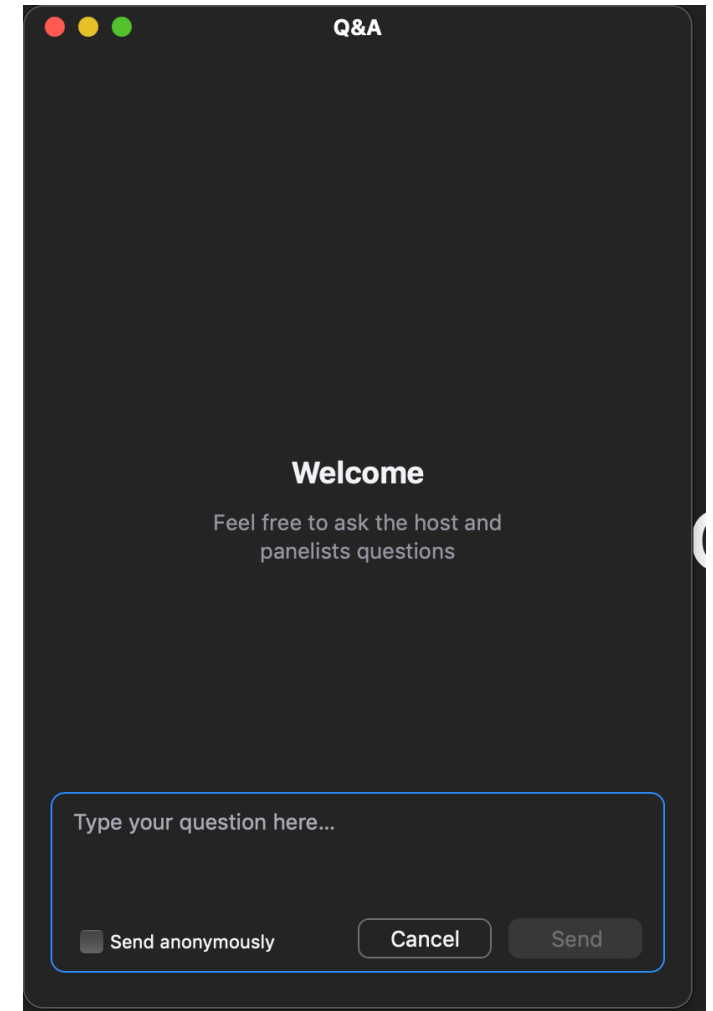
We appreciate the generous support of



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ZOOM Webinar Housekeeping

- Please submit your questions via the Q&A option.
- Due to the large audience for today's webinar, everyone has been placed on mute.
- If you have any technical issues, please contact Jane Donahue (jdonahue@aboutscp.com) or send her a message via the Zoom chat feature.



Hospital AT Home USERS GROUP™

Website: hahusersgroup.org

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Mastering Meds: Exploring Issues of Pharmacy in Hospital at Home

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Looking Ahead: Hospital At Home Beyond the Public Health Emergency

By the Numbers: Financial Models, Value Propositions, and Projections for the Next Generation of Hospital at Home Programs

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Can We Deliver Skilled Nursing Facility Care at Home? Should We?

Go Home and Go Big: Scaling Strategies for Hospital at Home Programs

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Rani E. Snyder, MPA

Vice President, Program
The John A. Hartford Foundation

Today's Webinar

Family First: Prioritizing Caregivers in Hospital at Home

HaH in the News



POLICY-ISH

'Hospital-at-home' trend means family members must be caregivers — ready or not

JULY 18, 2023 · 5:00 AM ET

By Kat McGowan

Modern Healthcare

NEWS BLOGS OPINION EVENTS & AWARDS MULTIMEDIA DATA & INSIGHTS NEWSLETTERS

January 10, 2024 04:00 AM

Is healthcare relying too much on family caregivers?

DIANE EASTABROOK [🐦](#) [in](#) [✉](#)

Family Caregivers: The Unrecognized Strength Behind Hospital at Home

Health Affairs Forefront – June 3, 2021 (Levine & Snyder)

HealthAffairs

What Can Hospital at Home Programs Do To Support Family Caregivers?

- Add family caregiver items to research agenda—including qualitative studies
- Explicitly recognize the family caregiver in the model
- Provide resources, tools, access to community services
- Quality metrics should include caregiver metrics



Today's Speakers



Ian Strasfogel

Former Caregiver
Mount Sinai at Home



Judith Norell

Former Patient
Mount Sinai at Home

Today's Speakers



Brittni Howard, MA

Research Assistant,
Hospital at Home and Caregiving Project
Icahn School of Medicine at Mount Sinai



Rita B. Choula, MA

Senior Director, Caregiving,
AARP Public Policy Institute



Pamela Saenger, MD MPH

Home Hospitalist,
Yale New Haven Health



The Caregiving Experience

Conversation with Ian Strasfogel and Judith Norell



Hospital at Home (HaH) Caregiver experiences

Brittni Howard, M.A. | Icahn School of Medicine at Mount Sinai

February 20, 2024

Presentation Objectives

- Study overview
- HaH caregiver component
 - Literature key takes
 - Study design
 - Help with caregiver recruitment

Moving Hospital at Home into the Mainstream of Health Care Delivery, Addressing Health Equity and Supporting Family Caregiving

STUDY –23-00180

PI: Albert Siu, MD, MSPH

MPIs: Bruce Leff, MD, David Levine, MD and Linda DeCherrie, MD

Qualitative Research Stream Leads: Abigail Baim-Lance, PhD and Ksenia Gorbenko, PhD

Sponsor: The John A. Hartford Foundation

Equity Component

Caregiver Component

HaH Caregiver Literature Key Takes

- Literature to date – overall, HaH caregiver experiences & effective models of care to engage them (Levine & Snyder 2021; Mason 2022)
- Several studies indicate that caregivers perceive HaH as safe, effective, with good outcomes and less caregiver stress (Leff et al 2007; Wang et al 2023)
- HaH might also cause stress, disruptions (Wang et al 2023), and that caregivers may need specific supportive mechanisms during HaH (Mason 2022)
- Caregivers as critical partners; further qualitative studies are needed to develop strategies to support them (Levine & Snyder 2021)

Current HaH Caregiver Component

Mount Sinai-led

- Aim to enroll 15-20 caregivers experiencing HaH nationwide
- Semi-structured 45-to-60-minute Zoom interviews

Interviews designed to address gaps in the literature

- Resources, knowledge, and training prior to and during HaH
- Initiation and experiences as a caregiver during HaH period
- Ways to strengthen HaH programs for caregivers

Current Caregiver Recruitment

Mount Sinai

- Recruitment:
 - Caregiver flyer shared by HaH frontline program staff to caregivers
 - Staff or caregivers complete a redcap form or email sent to Mount Sinai team to connect to interested participants
 - HaH User Group Basecamp postings
 - AARP and resource boards



So far, we have only completed 1 interview. We Need Your Help w/ Caregiver Recruitment

Concerned about IRB?

The Mount Sinai IRB considers that sites taking part are **not** involved in the research study; we can provide the determination statement.

One referring institution's IRB also reviewed and determined non-engagement in research.

If you would like your institution's IRB to review, we can help you gather:

- Mount Sinai Study Recruitment flyer
- HaH Caregiver Topic Guide
- Mount Sinai IRB's determination/explanation that sites are not involved in research
- The description of the intended population (caregivers, not patients)
- A description of your activity related to the study (providing flyer to caregivers)

Recruitment

Email for caregiver flyer and additional questions

Brittini Howard

Brittini.howard@mssm.edu

Survey Sign Up

<https://bit.ly/3wpMTBf>



HaH Caregiver Literature Key Takes

Author, date	Title	Key takes
Leff et al. 2007	Comparison of Stress Experienced by Family Members of Patients Treated in Hospital at Home with That of Those Receiving Traditional Acute Hospital Care	<ul style="list-style-type: none"> • Lower rates of stress/stressful situations of family members • Does not seem to shift burden of care from hospital staff to family members • Feasible and effective
Leff et al. 2022	A Research Agenda for Hospital at Home	<ul style="list-style-type: none"> • Survey of attendees at World HaH Congress 2019 • Key research domains include: HaH definition; measurement and outcomes; patient and caregiver experience; education and training; technology; regulation and payment; and scaling of HaH
Mason et al. 2022	Considering Caregivers' Needs in Hospital at Home Programs	<ul style="list-style-type: none"> • 60 heterogenous programs with diverse patient groups • Little known about caregiver experiences under AhCaH • Caregivers need support • Equity needs addressed
LeVine and Snyder 2021	Family Caregivers: The Unrecognized Strength Behind Hospital At Home	<ul style="list-style-type: none"> • Recognize and respond to caregiver needs • Include/collaborate with caregivers • Assess caregiver experience and instruction needs
Wang et al. 2023	Patients' and Caregivers' perceptions of the quality of hospital-at-home service: a Scoping Review	<ul style="list-style-type: none"> • Literature (24 articles reviewed) caregivers perceive types of HaH as safe, effective, and viewed positively - good health outcomes, continuity of the care team and daily life • Concerns/barriers: additional responsibilities, stress, disruptions...



Engaging Family Caregivers as Members of the Hospital at Home Care Team

Rita B. Choula, Senior Director – Caregiving, AARP Public Policy Institute

February 20, 2024

Considerations For HaH Programs

Ensure Choice, Access, and Equity

- **Voluntary participation (consent and assent)**
- Community admissions
- Eliminating barriers in order to serve patients across all demographics
- **Clear explanations of all services and how to access them, and all caregiver expectations**

Considerations For HaH Programs

Be Clear and Understandable to Patient and Family

Caregivers

- **Clear explanations of all services and how to access them, and all caregiver expectations**

Considerations For HaH Programs

Recognize and Support the Family Caregiver

- **Should not increase net caregiver strain relative to inpatient stay**
- **Assuring services and supports are available and provided to meet the needs of both the patient and the family caregiver during and after HaH stay**
- **Training family caregiver on medical tasks if interested and desired**

Considerations For HaH Programs

Allow for Appropriate Levels of Research and Learning

- Making claims data available to researchers
- **Studies to evaluate the impact of HaH programs on family caregivers**
- Reviews of access by demographic characteristics
- **Mechanisms to improve program based on assessments**



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HaH Tools for Caregivers

Pamela Saenger, MD MPH

CAREGIVER BROCHURES



INFORMATION FOR FAMILY CAREGIVERS



WHY IS MY FAMILY MEMBER BEING HOSPITALIZED AT HOME?

Hospital-level care in the home is not a new idea, but it has become more popular as 1) research has shown that hospital care in the home is as good or even better than hospital care in the traditional inpatient setting and 2) the COVID-19 pandemic created a greater need for care outside of hospital settings. Hospital at Home programs have demonstrated excellent outcomes for patients as well as high levels of satisfaction for both patients and caregivers. Your loved one was determined to be a good fit for home hospital care, and their care team believes they will benefit from treatment in their home, being able to be around their family or friends, and being able to sleep in their own bed.

WHAT DO I NEED TO DO?

PLEASE DO:

- Tell the care team what time of day is best to update you on the care plan, and how best they can reach you. They will record your preferred contact information.
- Ask the care team if you have questions about the care plan, your loved one's symptoms, or anything else you are wondering about. There is space to write down your questions below so that you remember to ask them when you speak to the team.
- Take care of yourself and your needs. Make sure you are eating, staying hydrated, and getting enough sleep. Here are some ideas to help you relax and recharge:
 - Take a break during the day and go outside for a 20-minute walk.
 - Listen to music that soothes you while you enjoy a cup of your favorite tea or coffee.
 - Call a friend you haven't spoken to in a while

Note: If you are feeling anxious, highly stressed, or having difficulty eating or sleeping, let the care team know as soon as possible.

PLEASE DON'T:

- Move any equipment and supplies in the areas from where they were placed by the care team. If you have any concerns about them, let the care team know.
- Forget to check in with the care team before administering any medications (including over-the-counter medications) to your loved one.
- Smoke in the same room as the patient. (Ideally, refrain from smoking throughout the duration of the home hospital stay).
- Take the patient anywhere outside the home unless first discussed with the care team.

How do I reach the care team? [CONTACT INFO HERE](#)

WHAT CAN I EXPECT?

Your loved one will get the same type of treatment and care that they would in the equivalent hospital. Members of the health care team will come and go throughout the day to assess and examine them, take vital signs, give medications, draw labs, provide therapies, and drop off or pick up equipment. The care team will keep you and your loved one informed of the schedule and whom to expect when.

HOW LONG IS THIS GOING TO LAST?

Typically, a home hospital admission lasts several days, but it could be as short as two days or as long as two weeks, or more. It all depends on how fast your loved one is recovering and how long they need hospital-level care. The care team will let you know when your loved one is approaching the end of their home hospital stay and can be "discharged."

WHAT HAPPENS AFTER "DISCHARGE?"

Your care team will help you and your loved one understand what comes next – including upcoming doctors' visits, changes to their medication regimen, and what to look out for to make sure they stay healthy. Your care team will also coordinate any additional needs like therapy and equipment, as well as determine the best setting for continued recuperation. In addition, your care team will coordinate prompt pick-up of equipment and leftover supplies.

WHAT IS MY ROLE?

If the patient has designated you as a caregiver, and you have agreed to accept that responsibility, we would consider you to be part of the care team. As long as the patient agrees, you are welcome to participate in care team visits. A home hospitalization does not require a caregiver to be in the home, and you may do as little or as much to care for your loved one as you would like and as feels right for you. As needed, the clinical care team will set up the patient with assistance in the home to ensure that they are well cared for and have the right amount of support while they are being hospitalized. If at some point during the hospitalization needs or preferences change and more or less help is necessary, do let the care team know.

TO SHARE WITH THE CARE TEAM:

We need help from someone with (check off digitally or circle by hand):

- transfers (e.g. bed to chair)
- mobility (walking assistance)
- toileting
- bathing
- personal hygiene (e.g. oral care)
- grooming (e.g. hair, trimming nails)
- dressing
- feeding
- meal prep, light housework

Questions I have for the care team:

-
-
-

Best times for the care team to reach me:

My preferred way to be contacted:

Notes:



Caring for Someone at Home



Your loved one's doctor believes it is safe for them to get care at home. An important part of this care is having someone who can help care for them at home. Your loved one believes that you are a reliable person who can play an active role in their care journey. Being a caretaker is a responsibility, but you can bring joy and hope to your loved one during their care journey.

How Can I Help?

Your loved one will have a care team available 24/7 to give them medical help. You can help by making sure that your loved one is following the care team's instructions. It's also important to speak up when you or your loved one has questions, concerns, or barriers. Here are some ways you can help:

- Prepare healthy meals for your loved one. Talk to the doctor to see if there are specific dietary guidelines you should follow.
- Talk to the doctor about activity level and encourage your loved one to be active if it is safe to do so.
- Keep up with housekeeping needs like laundry, mail, dishwashing, cleaning, pet care, etc.
- Run errands like grocery shopping.
- Make sure the home environment is clean and free of fall hazards.
- Set medication reminders, make sure medicines are being taken, and stored safely.
- Find activities that your loved one enjoys. Mental, spiritual, and emotional health are important, too.
- Don't hesitate to ask questions. Whether you have questions about technology or health care—the care team is there to help.
- Encourage your loved one. This can be an isolating and stressful time for them. Be able to recognize when they need encouragement and offer it when they do.

You can use your tablet to have a video or chat with a care team member 24/7. You can also use the telephone to contact the care team anytime. LOCAL NUMBER 214-632-8322 | TOLL-FREE NUMBER 833-369-1127 If your loved one has a medical emergency, call 911 right away.

Texas Health
Care at Home

Take Care of Yourself

Take care of yourself so that you can be a good caretaker for your loved one.



Actively manage stress.
Have a plan to manage your stress. Stay active, meditate, pray, or talk to a friend or therapist. Do what works best for you before the stress becomes harder to manage.



Care for your body.
Eat regular meals, stay hydrated, take medications, and vitamins regularly, get enough sleep, and stay active.



Stay organized.
Organize medical information so it's up to date and easy to find. Make sure legal documents are in order.



Stay connected.
Call or use video chat to spend time with family and friends. Isolation for you or your loved one can magnify negative feelings, so it is important to connect with others.



It's okay to need help.
Ask the care team for caregiver resources. You are not alone! Accept offers of help and suggest specific things people can do to help you.

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Care at Home

Xiomara Dorrejo, MS, AGPCNP-BC; Anne Lovelace, MBA, BSN, RN; Danielle McGrath, BS; Sarah Paez, MS, GNP-BC; Pamela Saenger MD, MPH
Available at: <https://www.hahusersgroup.org>

Texas Health Care at Home

CAREGIVER ROLE

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CAREGIVER-CARE TEAM COMMUNICATION

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Questions I have for the care team:

1.
2.
3.

Best times for the care team to reach me:

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Notes:



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LOCAL NUMBER **214-432-8322** | TOLL FREE NUMBER **833-369-1127**

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CAREGIVER WELL BEING

- Take care of yourself and your needs. Make sure you are eating, staying hydrated, and getting enough sleep. Here are some ideas to help you relax and recharge:
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Note: If you are feeling anxious, highly stressed, or having difficulty eating, the care team know as soon as possible.

Take Care of Yourself

Take care of yourself so that you can be a good caretaker for your loved one.



Actively manage stress.

Have a plan to manage your stress. Stay active, meditate, pray, or talk to a friend or therapist. Do what works best for you before the stress becomes harder to manage.



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Eat regular meals, stay hydrated, take medications and vitamins regularly, get enough sleep, and stay active.



Stay organized.

Organize medical information so it's up to date and easy to find. Make sure legal documents are in order.



Stay connected.

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It's okay to need help.

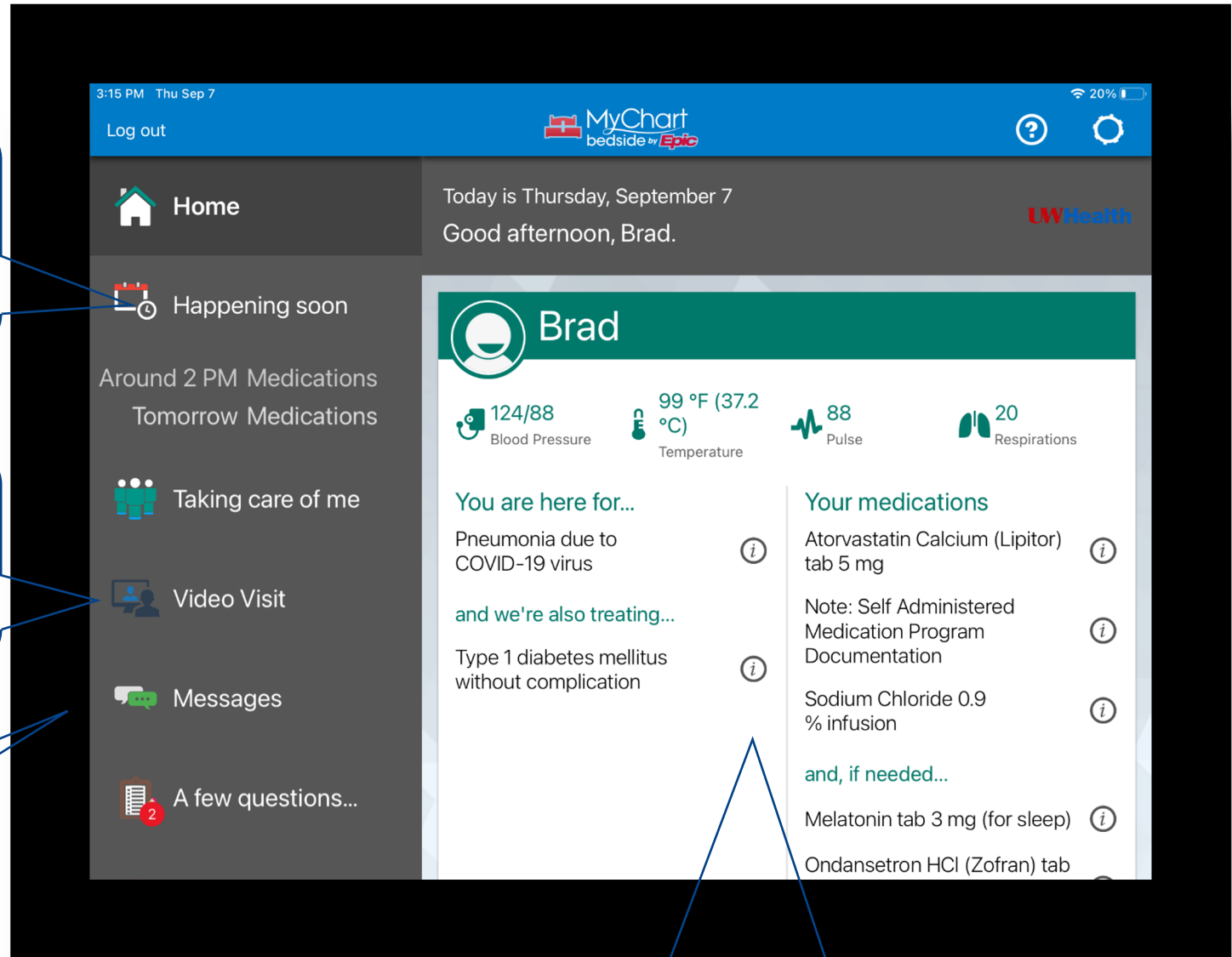
Ask the care team for caregiver resources. You are not alone! Accept offers of help and suggest specific things people can do to help you.

HaH TABLET

I really want to be present for the PT evaluation...

This is where I connect via video to the care team.

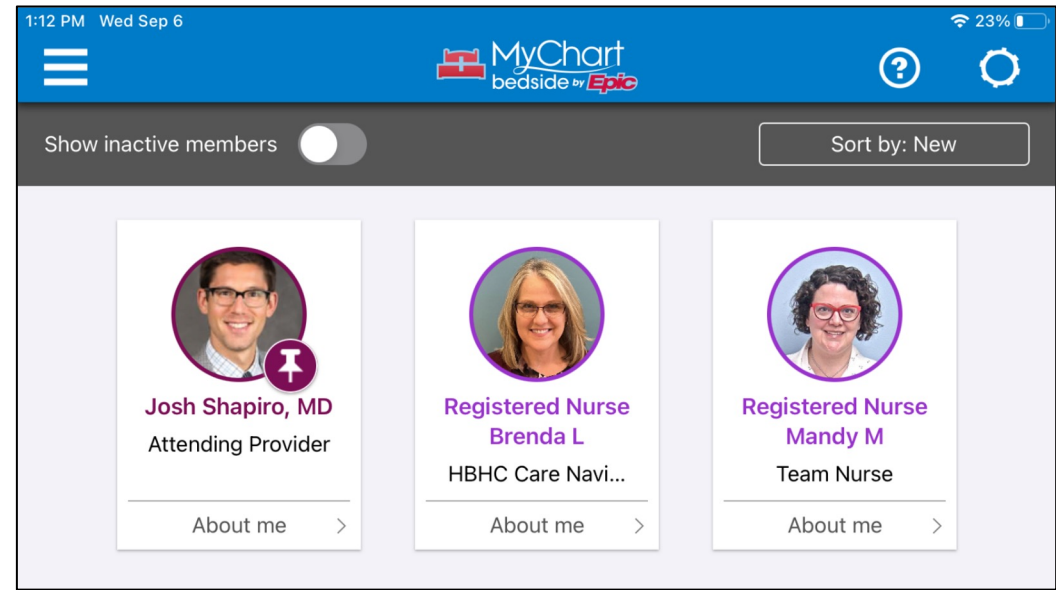
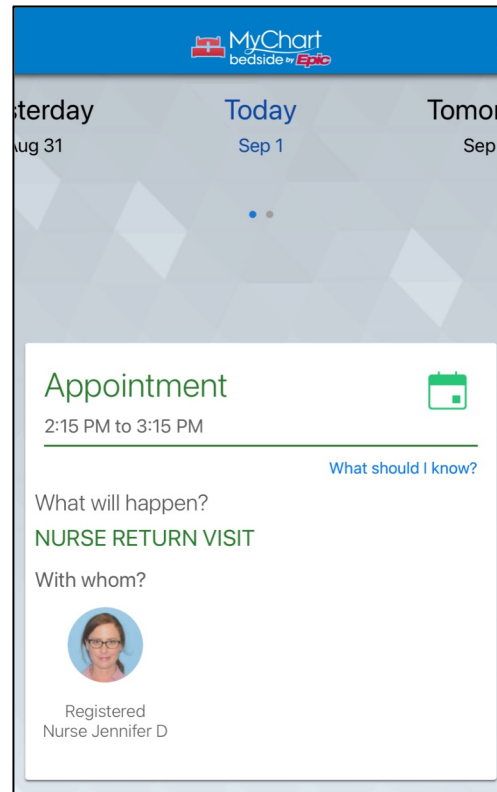
This is where I can send a message to the care team.



MyChart® is a registered trademark of Epic Systems Corporation.

This is where I learn about the diagnosis, latest vital signs, and medications.

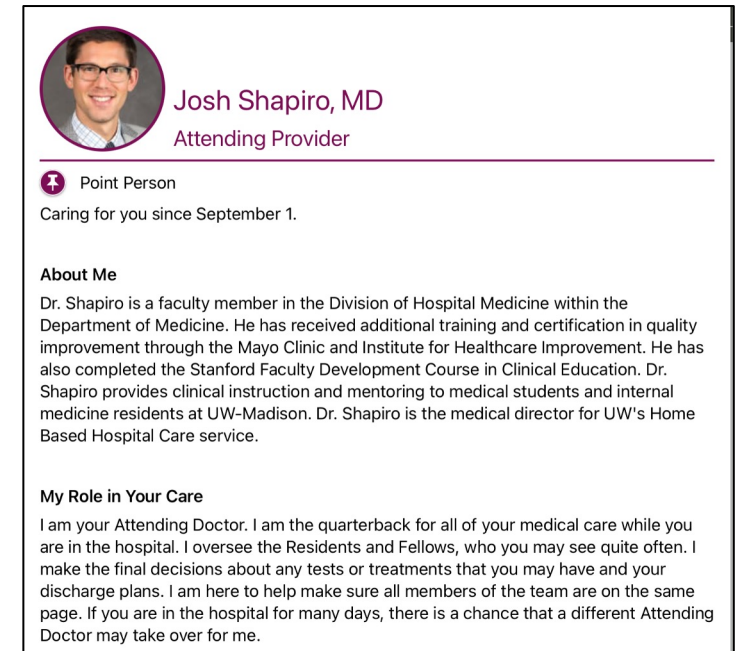
HAH TABLET



Visit Schedule

All visits (in-person and virtual) are scheduled in the EMR under the Home-Based Hospital Care department. The patient has full access to their daily schedule, along with details about the care team and the WHO, HOW, and WHEN of the visit.

Virtual visits (scheduled or ad hoc) are done with a click of a button, allowing easy connection to the care team and consulting providers.



HAH CAREGIVER RESOURCES



CLARIFYING THE CAREGIVER ROLE

HaH is still a new concept for many caregivers. Caregivers may not know what is expected/not expected of them. Aim to clarify the caregiver role and clearly state what assistance can be made available. Caregiver-specific materials should complement standard patient-facing information.



PROMOTING CAREGIVER WELL BEING

Aim to prevent caregiver stress and burnout. Provide assistance where needed. Remind caregivers about the need for self-care.



CONNECTING WITH CAREGIVERS

Connect the HaH patient and caregiver to the care team and provide them with options to engage, communicate, and learn. Help the caregiver identify key information that the care team should know, and prompt them to share it. Include the caregiver in care and discharge planning, and keep them updated.



QUESTIONS

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For More Information

- Hospital at Home Users Group
<https://hahusersgroup.org/>
- Hospital at Home Users Group Technical Assistance Center
<https://www.hahusersgroup.org/technical-assistance-center/>
 - **Featured Section – Resources for Family Caregivers**
<https://www.hahusersgroup.org/technical-assistance-center/program-operations/#supporting-caregivers/>

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