Can We Talk?
Advocating to Put People at the Heart of Health Care

Presented by
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Speakers

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Who We Are

National Patient Advocate Foundation (NPAF) represents the voices of patients and caregivers coping with serious and chronic illnesses nationwide as the advocacy affiliate of Patient Advocate Foundation (PAF).

- **PAF** provides direct case management, financial support, and educational services for primarily low-income patients and caregivers experiencing financial hardships due to illnesses.

- **NPAF** develops person-centered policies and drives evidence-based solutions promoting equitable access to affordable, quality health care at federal, state, and local levels through advocacy action and public and private partnerships.
What is person-centered care?
Putting People at the Heart of Health Care

Why “Person-Centered” Care?

“Patient-Centered” focuses on interactions in visits to manage diseases.

*Person-centered care* recognizes patients’ health problems as they see them.

- Focuses on the *whole person*
- Includes caregivers in the unit of care
- Provides foundation for better recognition of health problems and needs over time
- Facilitates appropriate care for these needs in the context of other needs
What matters to people?

How much is this going to cost?

Is that covered?

Are you in-network or out-of-network?

I don’t want my illness to financially ruin me.

Will I still be able to work?

How can I get to my appointment?

Who will help / teach me?

How can I control the pain, so that I can still do the things I love?
Palliative Care: The “Miracle Drug” Still Missing in Many Clinical Pathways

Rebecca Kirch, JD; Caitlin Donovan; Alan Balch, PhD—Column Editor

If palliative care were a drug, we would be holding hearings on Capitol Hill right now, demanding to know why everyone does not have access to its benefits. We would be writing think pieces, positing ways to bring down palliative care costs; we would be pushing the Food and Drug Administration for fast-track approval. We would be writing of the ways in which we should be incorporating palliative care into clinical pathways.

Instead, when most patients hear “palliative care,” they either do not know what it is, or they think it means care for the dying. Likewise, clinicians often associate palliative care with the end of life or “what to do when there is nothing left to do.”
What is Palliative Care?

- Team-based medical care focused on quality of life for the patient and family that provides relief from the pain, symptoms, and stresses of serious illness

- Appropriate at any age and disease stage

- Provided along with curative treatment as an added layer of support
What is the Issue?

• **Gaps persist in** professional, public, and policymaker **understanding** about **the benefits of providing palliative care** as part of disease-directed treatment throughout the illness experience.

• **Access to palliative care is limited** — particularly in community settings.

• **The specialist palliative care workforce is in short supply** to reach all patients and families in need.
Solutions

- **Federal**: Palliative Care and Hospice Education and Training Act (PCHETA)

- **State**: Palliative Care Advisory Councils

- **Local**: You!
What Can YOU Do?

How can we put patient and caregiver voices at the heart of health delivery reform?

Educate. Energize. Engage
Great Conversations
Start with Hello
What is Hello

• A conversation game created by Common Practice (commonpractice.com).

• It is an easy, non-threatening way to start a conversation with your family and friends about what matters most to you. It helps transform anxiety about dying into conversations about living.
When it comes to their health care, **people want involvement in evidence and decisions.**

**People** want to know:

- The full **truth,**
- The **risks** involved,
- The impact on **quality of life,**
- And that their **goals and concerns** are understood

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Findings from Institute of Medicine national survey of 1,068 US adults who had seen one health care provider in previous year, reported in 2013 Quality Cancer Care report: Charting a New Course for a System in Crisis.
THE ISSUE: Our current health care system focuses more on the disease (*what’s the matter*), instead of the needs and the quality of life (QOL) of patients and families (*what matters*).

THE SOLUTION: We need to reorient our health care system so it focuses on **both**. To do that, we need to provide patients, families, and health care professionals the **skills to be better communicators**.

### WHAT’S THE MATTER
- Diagnosis
- Disease-directed treatment
- Manage side effects
- Coordinate care and transitions
- Evaluate outcomes

### WHAT MATTERS
- Support QOL and function
- Minimize burdens on family
- Address concerns about role changes and illness stigma
- Acknowledge uncertainty, hopes, fears, and spiritual concerns

**Person-Centered and Family-Focused Care**
How Can Hello Help

Hello gives people the words to use.

Hello fosters communication with healthcare professionals and family members that help match treatments with personal goals.
Imagine the difference it could make for patients and caregivers if everyone on the care team knows …

- Something about them as a person — not just as someone with a medical problem

- What problems are most important to them

In order to provide you with the best care possible, what three non-medical facts should your doctor know about you?

How does this change the way care is delivered?

How does it change the way team members work together and with the patient and family?
As a Patient, Family Caregiver or Community Advocate, How Can I Use Hello?

**Play the game** with your loved ones.

**Share the experience** with others.
Let’s Play

Hello
Join Our Grassroots!

If you’re interested in becoming an NPAF Grassroots Volunteer or are interested in playing Hello in your community, visit www.npaf.org and click Get Involved.
Questions?
Thank you!

PLEASE CONTACT US:

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