Empowering Patients: How Self-Advocacy Improves Health Outcomes in Serious Illness

Interprofessional Grand Rounds

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Event Description

- People living with serious illness often face complex decisions, multiple clinicians, and significant symptom burden.
- Patient self-advocacy supports individuals in voicing their needs, asking questions, and participating in decisions that shape their care.
- This session introduces the core elements of patient self-advocacy, why it matters, and how it contributes to improved outcomes, including communication, symptom management, and satisfaction with care.
- Participants will learn practical approaches clinicians can use to strengthen self-advocacy during clinical encounters.

Learning Outcomes

By the end of this session, participants will be able to:

1. Define patient self-advocacy in the context of serious illness care

2. Describe how self-advocacy influences clinical and patient-reported outcomes

3. Identify practical strategies palliative care teams can use to support patient self-advocacy in everyday practice

Understanding Patient Self-Advocacy

What Is Patient Self-Advocacy?

- The ability to represent oneself, one’s needs, values, and concerns within the health care system.
    - Includes asking questions, expressing preferences, and participating actively in health care decisions.
    - Differs from independent patient or care team management
    - Reflects a partnership between patients, families, and clinicians that focuses on patient centered care.

Better Understanding of Their Condition & Options

Patients who actively ask questions and request clarification are more likely to understand their diagnosis, treatment options, and care goals.

Improving communication and patient information recall via a question prompt list: randomized clinical trial - PubMed

Patient Participation in Medical Consultations: Why Some Patients Are More Involved Than Others

Care That Aligns With Their Values & Priorities

Self-advocacy helps patients voice what matters most to them, such as comfort, independence, family involvement, or spiritual needs.

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[Engaging patients in decision-making and behavior change to promote prevention - PMC]

Increased Sense of Control and Empowerment

Engagement in self-management and advocacy skills is associated with higher self-efficacy and reduced health distress among patients with chronic illness.

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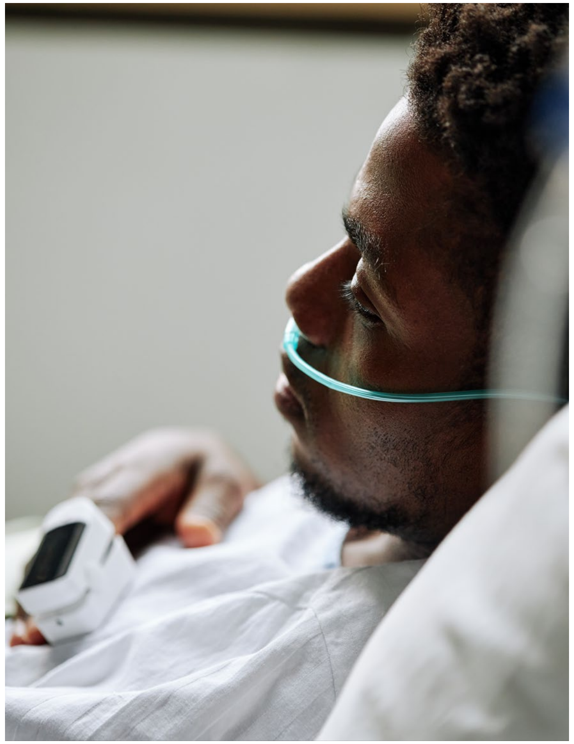
[Effect of a self-management program on patients with chronic disease - PubMed]

Improved Symptom Management

Recent qualitative research indicates that when patients effectively self-advocate, they are more likely to receive *person-centered care*, experience *reduced symptom burden*, and have a *better quality of life*.



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[Is self-advocacy universally achievable for patients? The experiences of Australian women with cardiac disease in pregnancy and postpartum - PMC]

Teaching & Supporting Patient Self-Advocacy

- Self-advocacy is a learned skill which the health care team can play a key role.
- Creating psychologically safe environments where patients feel safe, invited, and supported to speak up.
- Small, intentional practices during routine visits can significantly strengthen patient confidence and engagement.

Addressing Barriers to Self-Advocacy

Common Challenges Patients Face:

Power dynamics and fear	Health literacy and medical complexity	Language and communication barriers
• Some patients worry about being seen as “difficult” or fear negative consequences if they speak up.	• Medical language and complex systems can make it hard to know what questions to ask.	• Limited English proficiency or lack of interpreter support can silence patient voices. • Include info about interpreters

Addressing Barriers to Self-Advocacy

Common Challenges Patients Face:

Trust and prior experiences	Emotional and physical burden
• Past experiences of discrimination, dismissal, or bias may reduce willingness to engage.	• Pain, fatigue, anxiety, or cognitive changes can limit patients’ ability to advocate for themselves.

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Practical Strategies to Support Self-Advocacy for Seriously Ill patients

Prepare for Visits

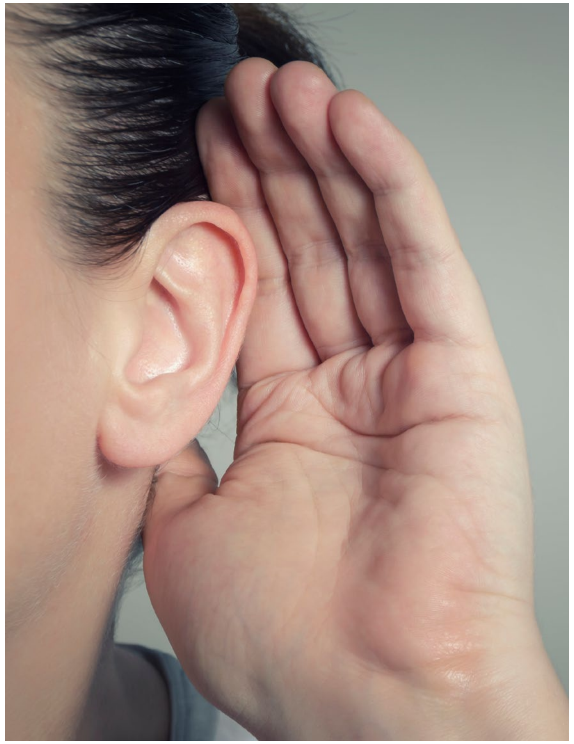
- Help patients clarify the purpose of the visit and what they want to address.
- Encourage them to write down questions in advance.

Bring Support When Possible

- Family members or trusted support people can help remember information and ask questions.
- Address "**displaced suffering**"
  - a phenomenon in clinical practice where a patient's family or medical team exerts pressure the patient to modify their medical decisions, not in the patient's best interest, but to ease their own emotional distress.

Use Teach-Back & Reframing

- Ask patients to repeat information in their own words to confirm understanding.
- Use reframing to ensure you understand the patient's experience

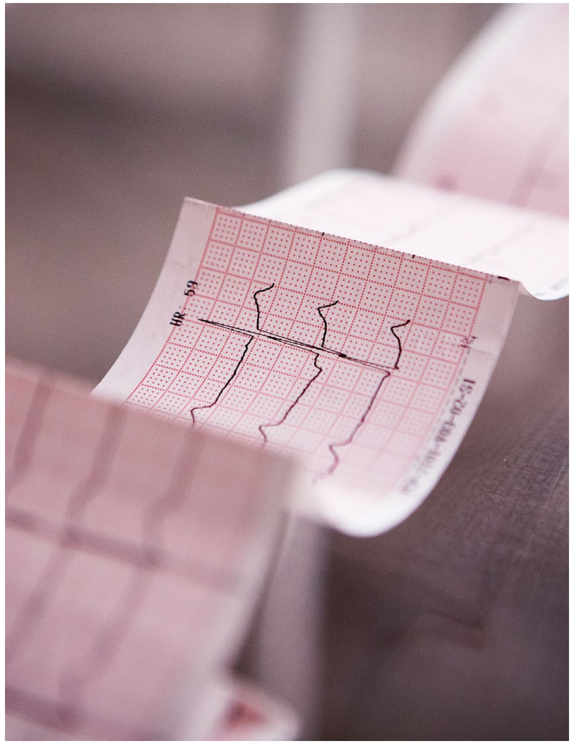


Invite Questions Explicitly

- Normalize question-asking by saying, **“What questions do you have?”** rather than “Do you have any questions?”

Share & Review Information

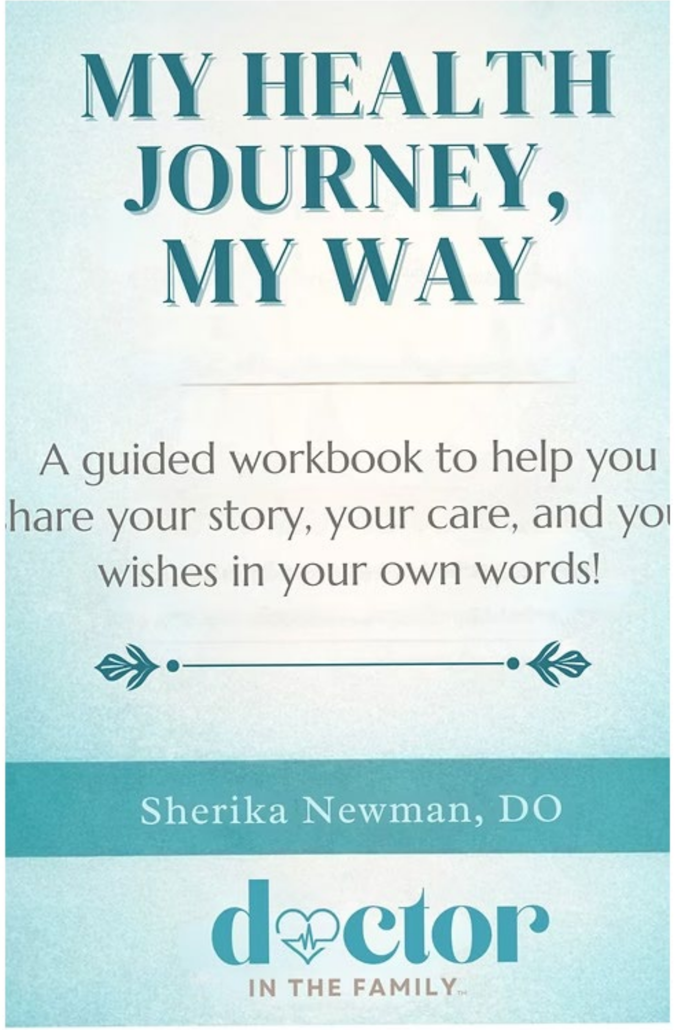
- Offer test results, written instructions, or educational materials when appropriate.
- Encourage sharing key information
    - Medication lists, prior records, and care preferences help ensure safe and coordinated care.



My Health Journey
My Way

A physician-created, fillable health workbook designed to help you organize your medical information, track hospital stays and clearly communicate what matters most.

This interactive PDF works on phone, tablet, and computer and can also be printed if needed.

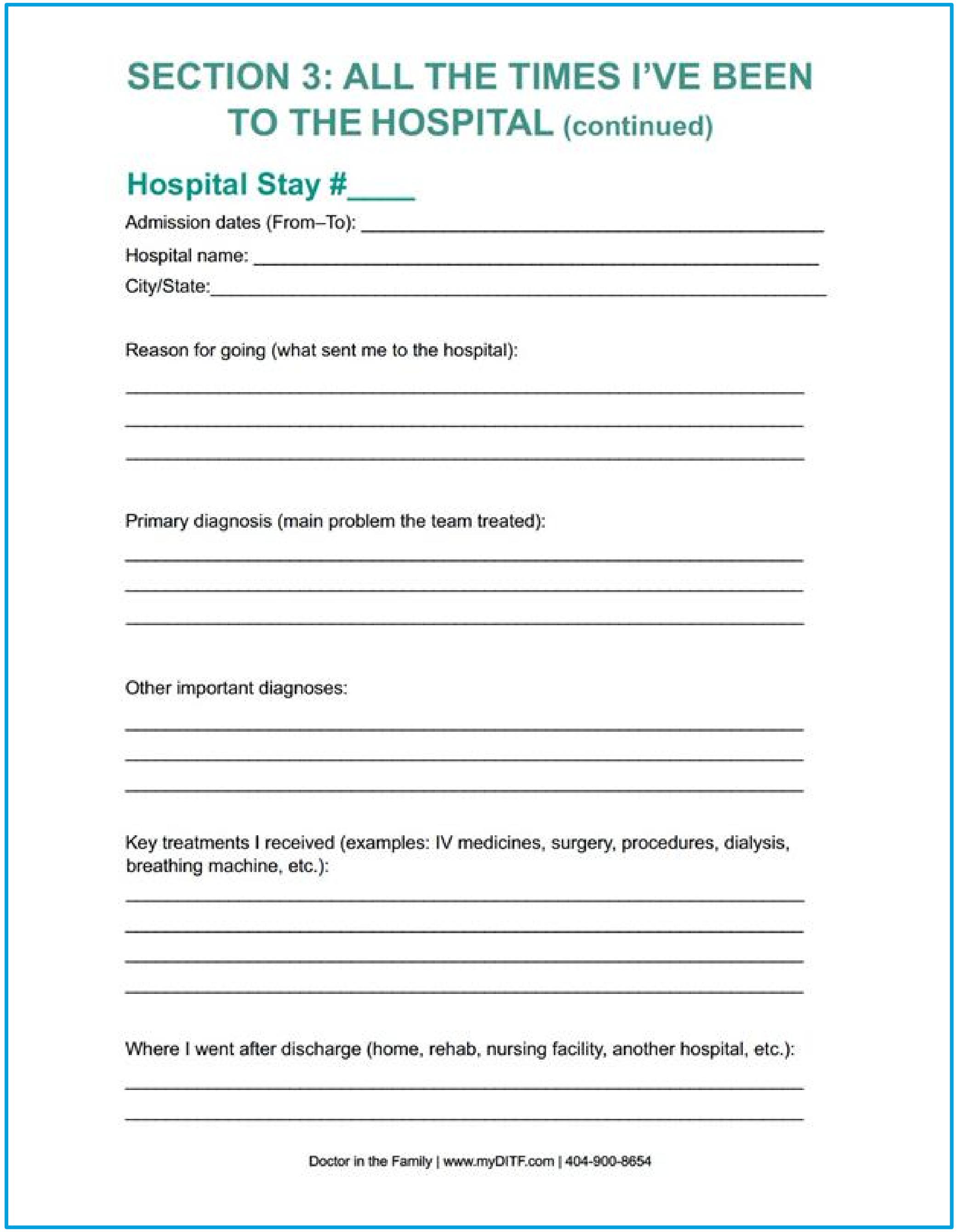


MY HEALTH JOURNEY, MY WAY

A guided workbook to help you
hare your story, your care, and yo
wishes in your own words!

Sherika Newman, DO

doctor
IN THE FAMILY



SECTION 3: ALL THE TIMES I'VE BEEN TO THE HOSPITAL (continued)

Hospital Stay #____

Admission dates (From–To): ______________________________________

Hospital name: ____

City/State:____

Reason for going (what sent me to the hospital):

____

____

____

Primary diagnosis (main problem the team treated):

____

____

____

Other important diagnoses:

____

____

____

Key treatments I received (examples: IV medicines, surgery, procedures, dialysis, breathing machine, etc.):

____

____

____

____

Where I went after discharge (home, rehab, nursing facility, another hospital, etc.):

____

____

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Case Study

Ms. L's Story

Ms. L is a 68-year-old woman with metastatic ovarian cancer, chronic kidney disease stage 3, and hypertension, admitted for progressive weakness, dizziness, poor oral intake, and new confusion.

On admission:

- Blood pressure: 86/52
- Creatinine: 2.9 (baseline 1.6)
- Sodium: 129

The Conflict

- She is started on IV fluids and admitted for **“acute kidney injury and failure to thrive.”**
- Over the first 48 hours, her kidney function improves modestly. The team documents that she is “medically stable” and begins planning discharge to a skilled nursing facility due to persistent weakness and limited participation in physical therapy.
- **Ms. L disagrees.**

Self-Advocacy In Action

On hospital day three, she asks to speak directly with the medical team. She arrives at rounds with a handwritten list. She states clearly:

- **“Every time I stand up, I feel like I’m going to pass out.”**
- **“I’m not weak because of my cancer. I’m weak because I’m dizzy.”**
- **“I was never this unsteady before this hospitalization.”**

She then presents three specific questions:

- **“Has anyone checked my blood pressure when I get dizzy?”**
- **“Why am I back on all three of my blood pressure medicines when I came in with low blood pressure?”**
- **“If the problem is dizziness, not cancer, why am I being sent to a nursing home?”**

Team Actions

The team pauses:

- Orthostatic vitals are obtained
- Supine BP: 114/70
- Standing BP: 76/44 with lightheadedness

Medication review reveals:

- ACE inhibitor resumed
- Beta blocker resumed
- Diuretic resumed
- All three were restarted on admission

Interventions are made:

- Diuretic is held
- ACE inhibitor is held
- IV fluids continued
- Physical therapy paused for 24 hours

Alignment

Over the next 48 hours:

- Dizziness resolves
- She stands without symptoms
- She walks 150 feet with therapy
- Urine output improves
- Creatinine stabilizes at 1.7

Discharge planning is revised:

- Ms. L goes home with home health instead of to a skilled nursing facility.
- At follow-up one week later, she is ambulating with a cane and resumes outpatient cancer treatment.

Teaching Point

This outcome changed because the patient refused a passive role, brought data, not just complaints, challenged diagnostic labels, questioned medication decisions, insisted the plan match her lived experience.

No consultant changed this outcome; no new test saved her. Self-advocacy functioned as a clinical intervention.

Key Takeaways & Q&A

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- Patient self-advocacy is a critical component of high-quality serious illness care.
- Strong self-advocacy supports better communication, symptom management, and satisfaction.
- Actively foster self-advocacy through simple, intentional practices.
- Consider Barriers for vulnerable patients & incorporate strategies into your workflow to create psychologically safe spaces for self-advocating.
- Support patient voice is both a clinical skill and an equity strategy.

Questions?

Resources

1. Self-Advocacy - CARE Center
2. https://uc-lend.med.ucla.edu/blog/blog-post-7-self-advocacy-in-healthcare-and-why-it
3. https://www.researchgate.net/profile/Jonathan-Sherbino/publication/289254703_Health_Advocate/links/59d2595c0f7e9b4fd7fc8706/Health-Advocate.pdf
4. https://journals.lww.com/lww-medicalcare/fulltext/2006/02000/self_advocacy_during_the_medical_encounter__use_of.2.aspx