

Partnering with Caregivers to Strengthen Engagement and Enhance the Diagnostic Process

National Academies: Engaging Patients to Advance Diagnostic Excellence: A Workshop
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Confusion

Gratitude

Anxiety

Joy

Love

Anger

Hope

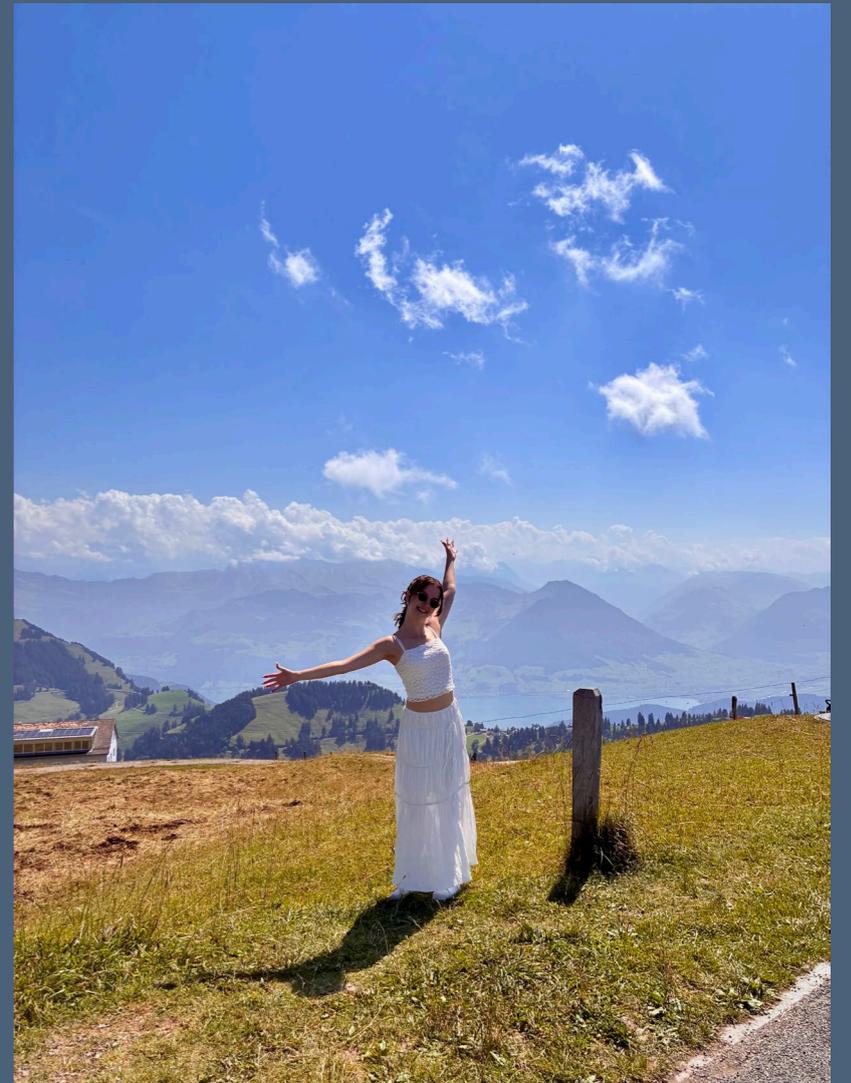
Pride

Fear

Exhaustion

Happiness





1.3 Billion people globally live with a disability and 80% are invisible¹

It can take 5 or more years on average for a person with a rare disease to find a diagnosis¹

12 million Americans (1 in 20) are misdiagnosed annually²



¹National Organization for Rare Disorders, February 2026

²National Institute for Health , 2014

What does engagement mean to you?

“A Mutually beneficial interaction that results in participants feeling **valued** for their unique contribution.”

thoughtexchange.com

Patients, **families**, and health care providers working in active partnership across various levels to help improve healthcare outcomes¹

Family engagement aims to build strong and effective partnerships with families with proactive communication and partnered decision making between healthcare providers and patients, families, and **caregivers**²

1. Carman KL, Dardess P, Maurer M, et al. Patient and family engagement: a framework for understanding the elements and developing interventions and policies. Health affairs (Project Hope). 2013 Feb;32(2):223–31. doi: 10.1377/hlthaff.2012.1133. PMID: 23381514

2. Centers for Medicare and Medicaid

Why is caregiver engagement crucial?

Successful patient and family engagement has potential to reduce costs, improve care processes, reduce provider burnout and improve patient outcomes.¹

- Can help patients prepare for visits
- Provider real-time observations and insights and bridge gaps that patient may have forgotten regarding symptoms, changes in condition, or past medical history
- Facilitate communication with provider and help avoid misunderstandings
- Help patient understand information or simply remember details of a visit
- Support shared decision-making and ensure patient individual preferences, values and needs are incorporated
- Improve follow through at home with care plans/treatments

1. Bennett WL, Pitts S, Aboumatar H, et al. Strategies for Patient, Family, and Caregiver Engagement [Internet]. Rockville (MD): Agency for Healthcare Research and Quality (US); 2020 Aug

Outcomes of Caregiver Engagement

- Active engagement of caregivers builds trust and stronger patient/provider relationships
- Helps manage chronic illness and increase patient satisfaction and clinical outcomes
- Reduces the risk of complications and reduce avoidable hospitalizations
- Provides patient with emotional support, decreases anxiety, and helps motivate them to stay engaged

Tips for Engaging Caregivers

- Identify the caregiver, ask who they are-don't assume
- Ensure they are included in the room and not excluded
- Validate their important role
- Make eye contact and include in conversations
- Seek caregiver input on their observations
- Ask if they have any questions or concerns
- Encourage shared decision-making
- Avoid medical jargon and ensure instructions are understood
- Thank them for being part of team and encourage continued communication



Support for Caregivers

Caregivers are at higher risk for health problems, stress, and depression¹

- Practice empathy: acknowledge emotional burden of caregiving
- Ask how the caregiver is doing: Stress and anxiety of caregiving can take a toll on their physical and mental health
- Provide supports: connect with support groups, social workers, and educational resources
- Help with coordination: don't leave everything in the hands of the caregiver
- Validation and Reassurance

“Don’t assign blame”

“Get to know the caregivers and their strengths and weaknesses”

“Always include caregivers in the conversation”

“Don’t treat caregivers as bystanders, they are part of the team ”

“Ensure consistent participation by caregivers to help understand and support decision making-as well as with bad news”

“Practice active listening and collaborating”

“Talk to me at my level so I understand”

“Help the helpers”

