

NOTES

Cape Meares Community Association
Aging with Grace - Preparing for End of Life Community Conversation
Advocating for Self and Others at End of Life
September 20, 2025

Why Self-Advocacy Matters (slide 5)? Participant responses.

- Not giving away personal agency.
- Get and receive the best health outcome.
- Learn what I don't know.
- Get and receive an honest report about what's going on.
- Continues confidence in one's agency
- Ensure a "yes" answer to concerns
- Feeling confident and being proactive with confidence
- A way to involve family
- A way to actively engage in the process: "know thyself."
- Opposite of being isolated - connection
- Make wise decisions, moving from curiosity to action
- Develops and builds confidence
- Not everyone knows everything, including physicians, care coordinators, or health care team members.

Sharing Past Healthcare Experience (slide 8). Participant responses.

- Inadequate information may be lost between providers or within the EHR and phone messages.
- The language we use may be familiar to us, but it means the same thing to the listener. This confirms a mutual understanding of what has been shared or asked.
- Safety - "being armed with information."
- Importance of questions
- Power of authority
- Culture
- Narrow, fractured focus, especially in time-limited appointments
- Trusted relationships with providers
- Value and importance of conversation, not just answering specific questions, following the focus on a "chief complaint."

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- Deflection/hackles up/defensive: how we approach providers with information, questions, and research.
- Self-direct versus defer or deference.
- Conscious and unconscious biases, especially from providers.
- Build one's case with notes and preparation, not simply a complaint. Share the whole picture/story with supporting evidence, e.g., symptoms, duration, and context.
- Emotionally misfit providers. Not everyone connects. It's essential, even critical, to experience an intentional connection with a provider.
- Vulnerability about what we share.
- Medical gaslighting
- Polarized medicine
- Healthcare workarounds
- Need to understand and speak their language
- Burned-out providers and stressed systems
- Identifying as a "client" versus a "patient."
- Expectations of research. Patient/client research and the capacity of providers to know the current research. Present not as a lack of competence or knowledge, but as curiosity and self-advocacy.