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ECHO

LEADING THE WAY 

Growing the Ability to Deliver Quality Healthcare to American Indian and Alaska Native People.

“Something's wrong... but you aren't listening”

*How caregivers and providers can improve communication
about a patient's changing cognitive status*

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Objectives

- I. Recognize verbal and non-verbal clues for caregiver concern
- II. Promote autonomy while obtaining comprehensive cognitive history
- III. Identify warning signs for early/moderate dementia



Check in

- **What experiences have you had with family concerns about changing cognition?**
- **How have families expressed these concerns in the past?**
- **How does the patient react?**



Case - Barbara

- Daughter calls PCP office asking to speak with SW
- Reports mother is having delusions – thinks she is pregnant, that there is a young boy living in her house
- Asking for support
- Geriatrics consult placed



Expressing Concern

Explicit

- Caregiver may call in with concerns; not reported by patient or unbeknown to patient
- “I’m worried about my mom’s memory” during a visit

Subtle

- Caregiver in visit shaking head out of view of patient while patient is speaking
- Caregiver silent while patient reporting information, may look uncomfortable



How would you approach this?

- **How comfortable do you feel asking explicitly about memory/cognitive concerns in front of the patient?**
- **What are some strategies you use to involve the patient while getting the full picture?**



Case - Barbara

- Meet Barbara and her daughter together
- Asked if she lives alone - "no I have a husband" but not able to recall his name
- When asked more about her husband and marriage history, states "Divorced on one and the second one I had to get rid of"
- When asked who manages the finances, states she's retired - "I'm retired and he's younger than me and he takes care of the money"
- Daughter states "you just said you pay your own bills" when they were talking in the waiting room



How to ask

- **I try to preserve autonomy/respect regardless of stage of dementia/cognition**
 - **“Would it be OK if I asked your ____ what they have noticed?”**
- **If they report an answer and the caregiver is shaking their head in the background**
 - **“Is it OK if I ask ____ what their experience has been?”**



Strategies

- **Most patients are OK with this – in my experience 90% will say OK**
- **If they don't say yes, or don't want information shared while they are in the room, can sometimes try to obtain information while patient is busy**
- **E.g. MA can engage patient in "Timed Get Up and Go" while you speak to caregiver**
- **Some caregivers will say they need to use restroom and flag you outside while you collect AVS**



Ethics

Patient needs to sign “Release of information for information to be released directly to others

What do you do if the patient is stating they don't want you to release information to a caregiver?

Not ideal, but can tell the CG you can listen to their concerns but not *share* information with them



Case - Barbara

- Ask Barbara if I can get her daughter's perspective
- Daughter reports they had to order cleaning people since house was in disarray
- When daughter visits there is 6 containers of creamer, pans that have been repeatedly used on the stove
- Daughter is pharmacist but isn't helping manage meds – didn't realize mom wasn't taking meds



Vague concerns

- **If caregiver is stating “something just seems off..they’re not themselves”**
- **Start with “Tell me more”**
 - **What are you noticing?**
 - **Do you have specific examples/situations that come to mind?**
 - **What are you worried might be happening?**



Normalizing

Depending on patient level of insight/awareness, I try to normalize the disconnect

“It is not your fault – as your brain is changing you may not remember the same things as your husband”

Family often needs education that behaviors are not intentional

- feeding dog repeatedly



What if the patient gets upset?

Some people living with dementia may get upset at questioning or hearing what their family is reporting

I try to deescalate and explain why I'm asking, offer reassurance

If necessary and they have 2 people with them, ask if they want to take a break while I continue speaking with their family



Warning Signs

- **Patient repeatedly missing medications**
 - No pharmacy fills in recent months
 - Asking for early refills
- **Unexplained weight loss**
 - Often early sign of forgetting to eat/how to prepare food
- **Pharmacy/front desk staff reporting odd behavior**
 - Patient picking up medication but then upset at pharmacy for not providing it



What To Ask

- **Ask explicit questions to family about changes they might be seeing**
 - **Misplacing objects?**
 - **Near misses while driving?**
 - **Getting lost while driving?**
 - **State of house – unusually dirty?**
 - **State of kitchen – spoiled food in fridge, empty fridge, used pots and pans not washed**
 - **Repeating self in conversation**
 - **Bills not being paid**
 - **Mood/personality changes**
 - **Gait changes**



Final Header



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