

Should the person with care needs attend the family meeting?

A key component of Our Family, Our Way is having the person with care needs attend and fully participate in the family meeting. Too often, their voice is missing or overlooked when deciding what's needed, wanted, and possible in the caregiving arrangement. We think this person's voice is important, maybe the most important! However, we also realize that in rare situations, it may not make sense to have the person with care needs attend the family meeting. This may be especially true when the they are living with advanced dementia. To help you determine whether the person with care needs can and should attend the family meeting, start by asking these three questions:

Is the person with care needs aware of their health conditions or diagnoses?

Family meetings are about open sharing. If the person with care needs is not aware of their health conditions or diagnoses, their attendance at the family meeting may not be helpful. For example, if a person living with dementia does not know (or remember) that they have been given this diagnosis, talking about memory issues or parts of their care and support that are affected by poor memory or judgment may be very difficult.

2 Does the person with care needs have insight into how their condition affects or limits them?

Even if a person is aware of their health conditions or diagnoses, they may not recognize their physical or cognitive limitations. In order to have an open conversation about how to create the best care and support arrangement, the person with care needs should have some awareness of why help may be needed. If they truly believe they don't have any limitations or needs for assistance, it may not be productive for them to attend the family meeting.

3 Will attending the meeting upset the person with care needs?

Talking about sensitive topics such as needing care and support can be difficult, and a certain amount of discomfort is normal. However, if discussing their limitations and needs causes the person with care needs to experience significant fear, confusion, anxiety, or stress, it may be better if they don't attend the family meeting.

4 If it's determined that the person with care needs should not attend the family meeting, they should still have a voice in the process.

It's important to consider how you can still ensure the voice of the person with care needs is heard and included when determining what's needed, wanted, and possible in the care and support arrangement. One way to do this is by asking them some open-ended questions prior to your family meeting and then sharing their answers during the meeting.

For example, you could ask:

- What's important to you when it comes to bathing?
- What are your favorite and least favorite foods?
- When do you like to get up in the morning and go to bed each night?
- How often do you like to have visitors?

By having the person with care needs answer questions about their preferences for their own care and support and using their responses to guide your family's care and support plan, you can help ensure your arrangement includes their voice.

To assist you in this, we have developed a resource called <u>All About Me</u> that is available on the Our Family, Our Way website.

To learn more and to access our tools and resources for caregiving families, visit the Our Family, Our Way website at www.MiamiOH.edu/ScrippsAging/OFOW