

Tips for an appointment with the family

TOOLS FOR HEALTHCARE PROFESSIONALS

It is important to be mindful of where the patient and family are at a given time. Some families have been on a long diagnostic journey or have been a part of the medical system for a long time, while others have been generally healthy and have encountered a serious diagnosis for the first time. Knowing and keeping this in mind can really help frame the conversations with the patient and family.

If meeting a patient for the first time please find out what they already know and understand about their disease and what are their views and beliefs about it. Some potential questions to ask are:

- What have you been told so far about your diagnosis/genetic report/symptoms?
- You have probably already thought this information over. What does the information you know so far mean to you and your family?
- What do you hope to get out of this appointment or care at this hospital?
- What has been your support system or what has helped you cope so far?
- What are your general goals of care? (examples: try anything that may help, prolong life as much as possible, assure as good a quality of life as possible, enjoy time with family to the extent possible, other goals)
- How much are you looking to be informed about your disease/mutation type? (examples: as much information as possible, only what's necessary now, other)

Be cognizant of the patient's/family's reaction to the information provided. Are they absorbing it? Do they appear scared or overwhelmed? Ask and adjust your approach if necessary.

Let the patient/family know what type of follow-up to expect, how to be in touch, and the anticipated response time. If the doctor is not the one who will be responding to follow-up inquiries, it is especially important to be clear so that the patient/family has an opportunity to ask all important questions during the appointment.

It is important to clearly communicate a plan for the timing of receiving and reviewing any ordered tests or labs. It can be difficult for patients to receive results they do not understand and have to wait for clarification.

When preparing a post-visit letter, it is imperative that it only contains information that was discussed with the patient during the appointment. It can be challenging to receive a letter several weeks after the appointment with new information or recommendations that were not previously discussed.

TIPS FOR SHARING DIFFICULT NEWS WITH THE FAMILY

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Patient families often say that the moment they got a diagnosis or other difficult news has stayed with them forever - they remember every word, every detail of that conversation. We hope these tips will help:

Know that the information you're about to share may forever split the life of the family into before and after. The significance of that can't be underestimated.

Share the news in person whenever possible, if not possible then by telehealth appointment or phone. Do not share the news via patient portal or in a written form.

Give family choices where possible. For example: "The MRI revealed some findings. Would you like me to display the images?"

Do not offer false hopes or exaggerate worst case scenarios. If you don't know, it's ok to say so. Families value honesty and often say that they appreciate the provider saying that they just don't know.

Leave space for questions, but assume that if the news is extremely difficult or unexpected, the family will likely have many additional questions once they start absorbing the information. Provide the family with the best way to get quick responses, at least at the initial stages. Consider checking in with the family the next day to ask how they're doing and answer any new questions.

Connect them with a social worker/case manager who can help connect patients to resources and coordinate care.

A hug or kind word, all matter and help the family to feel that they're not alone.