

**10 TIPS FOR QUESTIONS TO ASK  
IF YOU ARE CONSIDERING  
PARTICIPATING IN  
A CLINICAL TRIAL**



## 10 TIPS FOR QUESTIONS TO ASK

- What is the purpose of the trial?**
  - Understand why the trial is being conducted and what the researchers hope to achieve.
- What treatment or intervention is being tested?**
  - Ask if it's a new medication, a change to an existing treatment or a completely different type of intervention.
- What benefits can I expect?**
  - Get a realistic assessment of how the trial could potentially benefit you and other patients.
- What are the risks and side effects associated with the trial?**
  - Ask about both known and unknown side effects and how they will be managed if they occur.
- What is the trial timeline?**
  - Understand how long the trial lasts, how often you need to attend and how many tests or examinations are required.
- What alternative treatment options do I have?**
  - Ask about other treatments if you are not participating in the trial and how they compare to the trial treatment.
- Who covers the costs?**
  - Find out if the trial covers transport, treatment, medication and any other costs.
- What happens if I want to stop participating?**
  - Ask about your right to withdraw from the trial and if there are any consequences for doing so.
- How will my data and personal information be protected?**
  - Ask about data security, anonymity and who has access to your health information.
- What happens after the trial?**
  - Ask if you will have access to the results of the trial and if there is follow-up on your health afterwards.

**JUST A REMINDER**



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# THE GOOD CONSULTATION

## BEFORE

What do you do to document "your" symptoms - and are you prepared for the consultation?

- Personal medicine/emotion/pain diary
- Create a diary where you keep track of good and bad days.
- Take pictures of your physical challenges and bring them to the doctor

What do you do if you have a lot of questions?

Write down all your questions in a blog as they come, you can't remember them on the day. Sort them out and get an overview first and figure out which ones are most important.

Write the most important ones at the top and which questions can the nurse help with?

Which questions can only the doctor answer?

What do you want from the consultation and how will you achieve this?

Set a **goal** for the consultation and focus solely on this.

## HELPER

What are the pros and cons of an helper?

### **Advantages:**

- Four ears hear better than two and the extra ears always hear everything, where as a sick person you don't always get everything from the conversation.
- They can provide support and backing so you don't feel overheard, disempowered and invisible in the process.

### **Disadvantage:**

- The carer can take control and ask too many (irrelevant) questions if they don't know the illness well enough!

## UNDER

What do you do to ensure good co-operation with the doctor and a smooth consultation!

- Be on time!
- Be honest in your communication
- Be open
- Show respect and build trust
- Use humour to make the conversation flow
- Make DEMANDS! -that the doctor is prepared and has read your medical records.

What do you do if you don't understand your doctor's answer?

- Stick to your question, ask again and demand an answer (the good attitude)
- Ask your nurse when you come out of the doctor's consultation.
- Call the ward afterwards and repeat your answer to make sure you have the understanding for future treatment.

Check your patient record as needed, online (if possible) or get a copy from your GP or ward nurse.

How do you ensure that the dialogue with the doctor is structured?

- Set a goal the day before the consultation, what do you expect to get answers to!
- Set your expectations when you come in (tell them what you expect to take away from the consultation that day)

How can you show the most "true picture" of your physical, psychological or mental condition?

- Use your personal diary - the prepared notebook that fluctuates and takes pictures
- Be honest, but don't give the doctor a snapshot
- Don't tell them how you feel now, tell them how you've been feeling since the last time - in other words, remember the bad days too!

## SUPPORT

### **How do you ask good questions?**

- Ask one question at a time and give yourself time to think before you answer.
- Ask the doctor to explain in different words if you don't understand something.
- Write down your questions from home and bring them with you - preferably prioritised.
- Ask if you can get a written summary or a copy of important information.
- It's okay to say: 'I'd like to think about that and get back to you with answers.'

### **If you can't bring someone to the call**

- Ask if you can record the conversation on your mobile phone so you can hear it again.
- Take notes along the way or ask your healthcare professional to help you take notes.
- If possible - Send your most important questions in advance via email or the patient portal so they are prepared.
- Consider calling a nurse or patient counsellor afterwards and review what you heard to ensure understanding.

### **Emotional support - you are not alone**

It's perfectly normal to feel doubtful, nervous or overwhelmed. Considering participation in a clinical trial requires courage and thoughtfulness. Remember, you have the right to ask anything and to say no.

Consider reaching out to a patient organisation or an expert who can share their experiences and support you in your decision. There are also family support and patient counsellors in many regions.

### **Understanding research language - a small dictionary**

- Protocol - The detailed plan for the trial: who, what, how and when.
- Informed consent - The process where you are explained the trial and have to say yes (in writing) after you understand it.
- Placebo - An ineffective treatment used as a comparison.
- Arms - The different groups in the trial (e.g. one receiving treatment and one receiving placebo).
- Randomisation - Participants are randomly assigned to the groups.

## AFTER

What do you do if you can't understand or there is something you didn't understand after the consultation?

- Call the nurse if you are in doubt! They will be happy to help?
- What do you do if you experience side effects from new medication?
- Depending on the side effects, call either your department or your own GP.

Fingers crossed; all diagnostic questions go to your diagnostic department. and others are directed to your own doctor.

What do you do if the dialogue with your doctor goes wrong?

- Have a chat with your doctor to clarify the situation.
- Tell the nurse that you want to be connected to another doctor if you feel that the communication cannot be improved.
- Bring a helper ALWAYS!
- Seek help and guidance from the nurse.
- What can you do to better prepare yourself before your next consultation?

## PREPARATION

Preparation is **KEY!**





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