Consultation and Clinical Trial: You Can Make a Plan!

Plan ahead for your medical consultation and the possibility of enrolling in a clinical trial. It can help to talk to support staff at your doctor’s or consultant’s offices by phone so you will know if your expectations are viable. If the staff you speak with don’t have information about a certain area make arrangements to call back when it is available. This way all the preliminary material is out of the way and the focus can be on what is most important.

Make sure your medical records arrive before you do!

Before your visit explain what records you have and ask which of these they would like you to copy and make available. Usually you can get copies of MRIs or other diagnostic tests on CD. They are easier to carry with you or send than bulky films. If you choose to send your diagnostic results and films by courier or post be sure to call and confirm they arrived.

Your right to your own medical records

Every patient has the right to access their own data and understand the healthcare that involves them. Do you know what is in your records? E-Patient Dave has an excellent discussion on this topic here “You can ask to see or get a copy of your medical record & other health information” You can understand your treatment choices before you sign up for a clinical trial. Medical staff may not be able to release the records to anyone but you. Sending a friend, neighbor, or relative to
get them when you have not signed permission is frustrating for everyone. Contain expenses by finding out a range for costs and what will be covered before each procedure or visit.

Write questions down, take someone with you

Write down what you consider to be the most important things you want covered in your visit as chronic pain and injury can sidetrack us with emotion. You may get a compassionate response but it may eat away at the time available for an expert opinion. Remember to be courteous and thankful even when the news is not what you hoped for.

Plan a break away session

It is helpful to plan a nice dinner out or a treat for yourself for afterwards and if you can, take someone with you who will remember what the doctor says. The reason for this is it will be difficult for you to reconcile yourself to a short appointment when an injury or illness has taken over your life 24/7. Even though your appointment time may be quite generous, logic and rational thought cannot always be counted on, when you just want the problem fixed.

Sometimes there are no easy answers you may be asked if you would like to help others with the same affliction by participating in a clinical trial. You may be told there is a chance this could help you too. A chance is not a guarantee, no one knows for sure if the trial will help you or not. You can understand your treatment choices with the help and support of your doctor before you decide to enroll in a trial.

A clinical trial is not a treatment.

Many patients pin all their hope on clinical trials and will even pay to be part of one. The direct costs of a clinical trial should be borne by those who offer the trial. A
decision to enroll in a clinical trial needs to be informed and shared. Your physician is a part of your medical care team and can help you decide what is right for you before you sign up for a clinical trial.

Introductory Clinical Trials Video (4 minutes)

There is additional helpful information on Clinical Trials here and on why we need to be randomised here. ThinkWell has located a great Action Plan for preparing for a clinical trial on the Testing Treatments Interactive website which we have duplicated for your convenience below. The plan blends finding out about the effects of treatment that do exist to transitioning into the uncertainty of a clinical trial. It is important to realize that you don’t need this information all in one visit!

Action plan – 10 things you can do

1. Identify questions about the effects of treatment that are important to you.
2. Learn to recognize uncertainty; speak up; ask questions; seek honest answers.
3. Don’t be afraid to ask your doctor what treatments are available; what may happen if you choose a particular treatment; AND what might happen if you don’t.
4. When thinking about possible treatments, you may find the Ottawa information on decision aids helpful.
5. Use reliable websites such as NHS Choices. See also: “So what makes for better healthcare”.
6. Be a healthy sceptic about unfounded claims and media reports of treatment ‘breakthroughs’; about the way that ‘numbers’ are reported in the media – especially large
numbers in headline claims!

7. Challenge treatments offered to you or your family on the basis of beliefs and dogmas, but unsubstantiated by reliable evidence. Be wary of unnecessary disease ‘labeling’ and over-investigation – find out if the disease in question is considered high risk or low risk for you. Ask what would happen if nothing immediate is done.

8. Agree to participate in a clinical trial only on condition (i) that the study protocol has been registered and made publicly available (ii) that the protocol refers to systematic reviews of existing evidence showing that the trial is justified; and (iii) that you receive a written assurance that the full study results will be published, and sent to all participants who indicate that they wish to receive them.

9. Encourage and work with health professionals, researchers, research funders, and others who are trying to promote research addressing inadequately answered questions about the effects of treatment which you regard as important.

10. Encourage wider education about the effects of biases and the play of chance, and lobby your elected political representative and others about doing more to emphasize this in school curricula, beginning in primary schools.

Got Comments or Questions?