



1 **Let's Get Started!**



We know that you would rather be almost anywhere but in the hospital or the doctor's office, but since you are, this journal is here for you.

You are undoubtedly getting a tremendous amount of information from many sources right now, most of which is probably new and foreign, and sounding a lot like a language other than English! You are not alone! Please use this journal as your storage place for any and all information, handouts, and guides that are provided to you.

-  We have included many sample questions for you to consider. Only some of the questions may be appropriate for your particular medical situation. We hope that you will use these sample questions to come up with additional questions of your own.
-  We have also provided extra lines on many pages and encourage you to write down your comments, concerns, ideas, and open questions. It is also ok to leave this space blank, if you like.

Welcome to the Journal!

As you navigate through the medical community, here are four basic tips to consider. We'll guide you to:

 **Ask many questions.** Get an answer that you can repeat back and write down.

- › What does the doctor call the medical issue?
- › What is the name for the diagnosis (if there is one) in common, everyday terms that can be easily understood?
- › What needs to be done about it?
- › Why is it important to do that?

 **Write everything down** - and we mean EVERYTHING! This includes:

- › The questions you want to ask (You know, these are the ones you remember the minute after the doctor leaves the room.)
- › Doctor's names and contact information
- › Diagnoses and special instructions
- › Suggested procedures – alternatives, recommended times and places
- › Medication instructions

 **Find a place to sit down** to gather your thoughts together, and update your journal.

- › Take several moments to start digesting all that you have been told.
- › Discuss the information with a loved one (in person or on the telephone).
- › Write down any other questions, concerns, or uncertainties that come to mind.
- › Cross-out any items that do not pertain to your situation.
- › Remember: Doctors are human, too!

2 Now, What Do We Do?

Trust your instincts!

- ▶ If something seems odd to you, ask about it. If you are new to the hospital setting, it may seem that you just do not know enough about what is going on. We encourage you to ask many questions. Use this journal to write down your questions so that you have them handy when you need them.
- ▶ If you feel that something is just not right, do not be afraid to ask a nurse or doctor about what is going on. There are no stupid questions. It is better to ask your question, than to have something go unattended or happen in error.
- ▶ Try to have a family member or close friend with you. It is not uncommon to feel overwhelmed by all of the information that you are receiving from your treatment team. Having a trusted loved one nearby provides you with moral support and objective input as you make decisions with your treatment team.

**"The important thing is not to stop questioning.
Curiosity has its own reason for existing.
One cannot help but be in awe when
he contemplates the mysteries of eternity,
of life, of the marvelous structure of reality.
It is enough if one tries merely to comprehend
a little of this mystery every day.
Never lose a holy curiosity."**

~Albert Einstein²

² Anderson, Peggy, Great Quotes from Great Leaders, Celebrating Excellence Publishing, Lombard, Illinois, 1990, 91.

Find the Facts

Fill in the information that you have discovered so far.

-  What have you been told so far about the diagnosis or medical condition?
-  What have you been told so far about how the condition will be treated?
-  What have you been told about why it is important to treat the condition that way?

It's every parent's nightmare: the sound of a doctor's voice saying, "Oh, no! We have a problem here!" immediately followed by running feet as their newborn is rushed to intensive care to help him breathe. Little did the Sladeks know that their son would need over a dozen follow-up procedures before reaching adulthood.