GENERAL GUIDANCE

We want to help you to achieve two goals:

1) Make it easy for your doctor to see the big picture – your medical needs, expectations, and priorities.

2) Receive timely access to evidence-based medical care.

How?

- Bring a trusted friend or relative, or ask if you can tape the consult.
- Prepare: (1) referral, (2) authorization, (3) insurance cards, (4) emergency contacts, (5) doctor & local pharmacy contacts, (6) pathology report & slides, (7) concise written diagnosis, treatment and medical history, (8) medications & supplements list, (9) radiology reports & film, (10) allergy list (11) concise written list of your questions.
- Ask about additional services: (1) Care managers, (2) Mental health professionals, (3) Pain specialists, (4) Physical therapists, (5) Nutritional experts, (5) Social workers or (6) Support groups.

ASKING QUESTIONS

Honesty and diplomacy

Ask: "Is this a good time to ask questions, doctor?" Or, provide the questions in writing – with space for answers – so your doctor can answer your questions when time allows.

Honesty: Communicate honestly with your doctor and the nursing staff.

Find ways to show your appreciation for the skills and dedication of your health care team when it is evident.
QUESTION CHECKLIST

Use this list to help you prepare a concise list of written questions. Provide a copy for your doctor.

GENERAL QUESTIONS

- How often should I schedule visits?
- What prescriptions do I need & how should they be taken and stored?
- Prior to treatment or tests: Ask the staff to verify that your doctors, the healthcare facility, and the type of treatment or test you are receiving are all covered in your insurance plan, and check if the tests and treatments require pre-authorization.
- Can you refer me to a social worker that specializes in helping with finances and insurance matters?
- What is the best way and time to communicate with you about my concerns? Phone? Fax? Email?
- What materials or resources can you provide to help me to become informed about the disease and the treatments?
- What resources are available to me to help me cope with the anxiety I feel?
- What other resources are available to me: Nutrition? Psychosocial? Sexual?
- May I record what you say on tape so that I can be sure not to miss what you say, …. Or do you mind if I take notes?

TREATMENT QUESTIONS

- What is my diagnosis? And can you please provide me a copy of the pathology report.
- How widespread is the disease (the stage)?
- Does the disease require prompt treatment and why?
- Can the disease be cured?
- What are the symptoms of the disease, and which indicate a need for treatment?
- What are my treatment choices?
- Do you offer radioimmunotherapy as a treatment option?
- Are new treatments under study? Would a clinical trial be appropriate for me?
- Which treatment or treatment sequence do you recommend? Why?
- What are the chances that the treatment will be successful?
- Is the collection of stem cells indicated before or after this treatment? When is the best time to consider stem cell harvesting, in general?
- How long will the treatments last?
- How long will it take for the treatment to begin working against the disease?

EXAMPLES: Antibiotic therapy for H-pylori can take 12 months or more to show a result against MALT lymphoma; and Rituxan therapy can take many months before an optimal response is seen.

- How easy is it to administer; will it disrupt my normal life or ability to work?
- How durable is the response likely to be?
- What signs will indicate that the therapy is beginning to work or that it is not working?
- What tests will be used to measure or gauge an early response to treatment?

SIDE EFFECT QUESTIONS

- What side effects should I expect?
- What side effects should I report to you immediately?
- What are the side effects I may experience that are not dangerous?
- Will there be side effects that may prevent me from using other important treatments, or make it more difficult to harvesting of stem cells in future?
- What signs or changes should I report immediately?
- What is the best way to contact you about side effects?
- How will I feel during therapy, and will it affect my ability to do normal activities?
- Can I have sexual relations during this treatment?
- What can I do to minimize risks during therapy, such as risk of infection?
- Will the treatment or withdrawal from treatment cause depression?
- What foods, supplements, procedures, or medications should I avoid during treatment?

TEST QUESTIONS

- What tests will you order?
- What will the tests show or indicate?
- Will you provide copies of the results?
- How often should I receive these tests?
- What toxicity and/or risks are associated with this test – or the repeated long-term use of this test? Is there a safer alternative?
- What changes or symptoms may indicate the need for tests?
- What test results indicate a need to initiate or change treatment?
- When is a bone marrow biopsy indicated?
- What steps will you take to minimize the discomfort and anxiety associated with the bone marrow test?