

BIG PICTURE QUESTIONS

Guiding the Approach to Treatment

By PAL and Our Advisors

Board of Directors

Mike Abrams
Linda Gerstley, PhD.

Jama Beasley
Carol Lee

Scientific Advisors

Maurizio, Bendandi, PhD, MD

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University of Chicago

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MS, RD, CDN

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Columbia University

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Mike Lubrecht

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Founding Member: Allan Marson, Esq.

Patients Against Lymphoma

Patients partnering with scientists to make progress against lymphoma



3774 Buckwampum Road,
Riegelsville, PA 18077

Phone: 610-346-8419 | Fax: 801-409-5736
Support@Lymphomation.org

non-profit 501 (c) (3) organization

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INTRODUCTION

Treatment consults can be challenging – especially when there are many options to consider, and when the type of lymphoma we have can behave in different ways.

Consults can be fast-paced depending on our physician's case load. We may often feel stressed. So it's common to forget to ask an important question or to inform about symptoms, our quality of life, or our personal preferences.

To help, we urge you to prepare and provide **your questions in writing in advance – in a concise format;**

and to start the consult by asking **"if this is a good time to go over my questions?"**

By taking these two basic steps we are showing respect for our doctor's time; and helping him or her to "get up to speed" quickly ... to use the time to focus on problem-solving and asking key follow-up questions.

The goal of this material is to help to optimize your treatment consult ... in order to choose an evidence-based approach to treatment that's specific to your diagnosis and unique clinical circumstance.

Ideally, the recommendations will take into account your quality of life, the most appropriate treatment goals, and your personal preferences – which can be especially relevant when we have multiple choices.

BIG PICTURE QUESTIONS

Also bring a trusted loved one to help optimize treatment consults

1) What is the natural history of the disease?

(aggressive, indolent or slow growing, variable)

The likely clinical course can determine the approach, goal, and timing of therapy. For example, for aggressive lymphomas the most appropriate goal of therapy is usually to cure -- with therapy starting immediately.

For lymphomas with a variable clinical course a period of observation might be needed to judge its behavior and the most reasonable approach.

2) What are my individual risk factors?

(age, general health, secondary conditions)

Such factors can influence the goal or approach to therapy. For example, if we are frail a modified protocol or a clinical trial might be more appropriate than standard therapy.

3) What is the standard approach for my type of lymphoma? Is it effective?

(curative, highly effective, variable, unsatisfactory)

This can often determine if a clinical trial should be considered. For example, if the lymphoma is not likely to be cured with standard therapy and the natural history is aggressive, a clinical trial might be an appropriate choice.

4) What is the most appropriate goal of therapy for my specific case?

(cure, durable remission, management, palliative)

The goal is often based on answers to questions 1, 2, 3. For example, if the natural history indicates that cure is unlikely with standard therapy, and the clinical course is often indolent, and you have a low tolerance for risk ... a management goal could be the most appropriate choice for you.

Sometimes, one thing is what the consultant thinks and another what the patient thinks. Differences might be reconciled, but the two should be on the same "page" even in case of "disagreement" (or change consultant, of course).

5) What's the level of evidence for the proposed therapy?

What study results have been reported for patients with my diagnosis and clinical circumstance? Were the studies large enough? Did they have controls (randomized) or were they single-arm studies?

Is there an expert consensus favoring the proposed approach? If not, what are the key areas of disagreement?

What are the known risks and potential benefits for the recommended therapy?

What are the key tradeoffs when multiple protocols are offered as reasonable?

6) When should I start treatment?

(based on answers to questions 1, 2, 3, and 4)

The natural history of the lymphoma, but also how it behaves, can determine how soon treatment is needed.

For example, for indolent lymphoma, close observation without treatment (watch and wait) can be appropriate.

7) How do my priorities and preferences enter into the decision?

On this question YOU are the expert!

In situations where more than one approach is reasonable, I may prefer a treatment that:

- Is most likely to help my symptoms to resolve quickly
- Provides the best chance for a cure
Will I accept certain long term risks and toxicities if there is a chance for cure?
- Has the least risk of death
- Has the lowest short-term risks and fewest side effects
- Will be the least disruptive to my normal life, such as can be administered at home
- Will have the least negative impact on my quality of life
- Is most likely to be the best approach in the long term (if known).

8) What clinical trials might I consider? What is your role in them?

Clinical Trials can be based on minimal or high levels of evidence. They can sometimes align well with our treatment goals and compare well to regular treatments in respect to the potential to meet our treatment goals.