

Getting the most from your visit in a changing medical environment

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Things have changed....

- Many of our visits are now 'virtual', whether this be via Zoom or telephone
- We cannot always bring loved ones to visits for support
- Visits are probably not as long

What should stay the same for you?

- Your priorities!
 - Your 'list' of questions
 - A 'report' on your condition
 - A good understanding of where you are, next steps?

BEFORE the visit

- What do you MOST want out of this visit?
- How much time will you have (hint, a 60 minute visit is really more like 45)
- Have your records arrived to be reviewed?
 - Notes
 - Labs
 - Imaging studies
 - Pathology reports

BEFORE-Part 2

- Do your homework:
 - Learn our myeloma language: M protein, free light chains, immunoglobulins
 - Learn our 'normal' lab language: White blood cells, red blood cells, platelets, neutrophils. REMEMBER there are ranges
 - How is YOUR myeloma 'tracked'?
 - Some people are best tracked with M protein/M spike
 - Some people are best tracked with light chains
 - Some people are best tracked with urine
 - Some people are best tracked with imaging such as PET scans

DURING the visit

- Is it ok to record? Get permission.
- Is it time to treat/change therapy?
- Should you consider a clinical trial?
- Know what you are and are NOT willing to do for therapy (travel distances/long infusions, frequent visits, extra procedures like bone marrow biopsies)

Pros and Cons of Clinical Trials

- Pros

- Clinical trials 'move the needle forward', you can be a part of that!
- Much of the treatment (not all) is covered by the sponsor of the trial
- There are many more labs, contact points with clinic to monitor how you are doing
- You are likely receiving some of the best, cutting edge therapy that is not yet available
- It can feel like you are 'doing something' by participating in the process

Pros and Cons of Clinical Trials

- Cons

- There are many more labs, contact points with clinic to monitor how you are doing
- This treatment may not be superior-not all new treatments are better
- You may experience side effects

CONCLUSION

- These are just suggestions. Find what is right for you.
- Take the time to do your homework before the visit. Prepare in the way that your clinic does for your visit
- Be cautious about where your information comes from. Trust only vetted resources (Myeloma Beacon, International Myeloma Research Foundation, etc)

HOMEWORK:

- Prepare for Dr. Bensinger's presentation on the best of ASH (American Society of Hematology)
- Know key terms: PFS (progression free survival) ORR (overall response rate) median, etc

Thank you for your attention!