

Making the most of your consultation

PNH Question prompt List

This is a helpful list of questions, which you can use at any point in your PNH journey - from diagnosis to various forms of treatment, including clinical trials.

Frequently, patients do not think of specific questions until after the consultation is over or until they read specific information booklets. This is perfectly normal as consultations are tense times, where your mind can go 'blank'. Using such a list may help to cover all topics you need to be aware of.

Most of this list was compiled by patient groups, working in conjunction with researchers, to help PNH patients gain greater control over the flow of information in consultations.

We adapted the list for Canada and added a few comments - to facilitate the discussion with your hematologist.

Just diagnosed with PNH

- How sure are you about the diagnosis of PNH?
- Can you explain what PNH is?
- Do I need any other tests before we can decide on treatment?
- Can you explain the types of tests used to diagnose PNH?
- Do I need to see any other types of doctors?
- Are there factors that could affect my outlook or treatment options?
- Can I have a print out of my blood results?
- What are the specifics I should focus on when looking at my blood results?
- Are there other disorders/diseases that are associated with PNH?
- How many people a year are diagnosed with PNH?
- Is it contagious? Should I be concerned for those around me?
- Am I able to travel by plane, both within Canada and internationally?

When deciding on a treatment plan

Support groups and PNH experts do recommend an additional opinion when it comes to rarer blood cancers like PNH, as not all hematologists can be PNH specialists. This can also be helpful to gain access to a wider range of clinical trials.

- How much experience do you have treating PNH?
- Should I get a second opinion before starting treatment?
- Can you suggest a doctor or Centre of Excellence?
- What treatment choices do I have?
- Do we need to treat the PNH right away?
- Which treatment, if any, do you recommend, and why?
- What should I do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- What are the risks or side effects of the treatments that you recommend? How long are they likely to last?
- Will treatment affect my daily activities?
- What is the outlook for my survival?
- What do most people choose as treatment?
- How many people have you treated for PNH?

- At what percentage does the medical community recommend being treated?
- Are there any requirements for being treated with Soliris®?

Clinical Trials

- Are there any clinical trials I ought to be aware of before deciding on a standard treatment?
- What travelling is involved? I am, (or I am not) able to travel far for a clinical trial.
- Will I be treated any differently if I enrol in a trial?
- What are the top research hospitals/centres for PNH trials?
- Are there any benefits or risks associated to enrolling in a clinical trial?
- Will you still continue to oversee my care if I do enrol in a clinical trial?

During and after treatment

Once treatment begins, you'll need to know what to expect and what to look for. Not all of these questions may apply to you, but getting answers to the ones that do may be helpful

- How will we know if the treatment is working?
- What type of follow-up will I need during and after treatment?
- How long does it typically take for treatment to start working?
- Is there anything I can do to help manage side effects?
- What symptoms or side effects should I tell you about right away?
- Do I need to change what I eat during treatment?
- Are there any limits on what I can do?
- Should I exercise? What should I do, and how often?
- What would my options be if the treatment isn't working?
- Is there anything I can do to increase the chances of treatment working?

Other support

Can you suggest a mental health professional I can see if I (or my spouse/partner) start to feel overwhelmed, depressed, or distressed? Where can I find more information and support? *AAMAC website is a useful tool and support for diagnosed PNH patients.*

Top tips

- Take a pen and paper and write your questions down.
- With the permission of your physician, you can sometimes electronically record the consultation, if you feel you cannot take all the information down.
- We recommend you attend most consultations with a family member or friend, as it can be difficult to remember all that is said in a conversation.
- Find a peer who has been diagnosed with PNH and understands what you're going through - ask your doctor or search online for groups; you're not alone.