



Patient Checklist For Pemphigus/Pemphigoid

Often when patients are first diagnosed with pemphigus/pemphigoid or these diseases are being considered as a diagnosis, there are a usually a lot of questions. We have prepared this questionnaire to help you get the answers you need. Go through these questions thoroughly before your doctor visit. You may not need all these questions answered on the first visit.

DIAGNOSIS

1. Has an immunofluorescence test been done on the biopsy? []Yes []No
2. Will you take a blood test to confirm the presence of antibodies? []Yes []No
 - a. What will you look for in an antibody test?
 - (1) Antibodies to desmoglein 1 _____
 - (2) Antibodies to desmoglein 3 _____
 - (3) Other Antibodies _____
 - b. When the antibody titer test is done, can you tell me the results? []Yes []No
 - c. How important is the titer count in treating the disease? _____
3. Is pemphigus/pemphigoid contagious? []Yes []No
Please explain:

4. Is pemphigus/pemphigoid inherited? []Yes []No
If there is a genetic connection, do my children have to worry about getting the disease? []Yes []No
5. Have you treated pemphigus/pemphigoid before? []Yes []No
If so, how often do you see a patient? _____

TREATMENT

1. Will the first drug you prescribe for me be a steroid? []Yes []No
If Yes, how many milligrams are you prescribing? _____
2. Why are you recommending _____mg a day?

3. When during the day should I take steroids? _____Morning _____Afternoon _____Night
4. Should I take steroids with food? []Yes []No
5. I know that steroids can cause serious side effects such as osteoporosis, thinning of the skin, loss of muscle tone, possible psychological problems, high blood pressure, stomach irritation, high cholesterol. How can I cope with these side effects?

6. Since you are prescribing steroids, should I have a bone scan?. []Yes []No
If yes, how often? _____
7. Since steroids can cause stomach problems, should I take a medication such as Pepcid, Zantac, Tagament? []Yes []No

8. If I am on steroids only, how often should I have a blood test? _____
 What should we look for in a blood test? _____

9. Will you prescribe []Imuran, []CellCept, []Cytoxan, []Dapsone, []Plaquenil, []one of the cycline drugs, []niacinamide, [] other
 a. How many mg will you prescribe? _____
 b. What are the side effects of these drugs?

10. If I am on immunosuppressive drugs, how often should I have a blood test? _____
 a. What should we look for in a blood test _____
 b. If the blood test shows a problem, can I reduce my drug instead of going off of it completely? Or, is there something else I should do?

GENERAL QUESTIONS

1. Should I find an Internist to help me deal with drug side effects? _____
2. I know that certain blood pressure medicines can trigger pemphigus. If I need this kind of medication which ones should I avoid? _____

3. Are there any foods I should stay away from? _____
4. Do you recommend a specific diet? _____
5. Can I go out in the sun? _____
6. Should I exercise, and if so how much should I do, and how often? _____
7. Should I consult with an Ophthalmologist? _____
8. Is stress an important factor? _____
9. Are there any vitamins or supplements I should take or stay away from? _____
10. Should I take Calcium supplements []Yes []No Vitamin D []Yes []No
11. Can I take immune enhancing drugs? _____

The International Pemphigus Foundation suggests that you keep a diary tracking the course of your disease; any adverse reactions to medication, your diet and any physical problems your experiencing. This information can be very useful in planning your course of treatment. Learning to live with pemphigus and pemphigoid is a process. It takes time and patience. Your physical and emotional strength will be challenged. Keeping a diary may help. You may feel the need to talk to someone. Please feel free to call us, or you may want to consult a counselor or a therapist.

Please tell your physician about the Foundation.

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