



PATIENT CHECKLIST

Questions you should discuss with your doctor

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Undiagnosed or newly diagnosed patients have lots of questions The IPPF has prepared this questionnaire to help you get the answers you need. We recommend you go through these questions **before** your doctor visit, and then share/discuss them with your doctor to help you find answers to questions you may not have known to ask. *You may not need or be able to get answers for every question on the first visit.*

BASIC/INTRODUCTORY QUESTIONS

Have you treated Pemphigus and Pemphigoid before? [] Yes [] No
If so, how often do you see a patient(s)? _____

Is Pemphigus or Pemphigoid contagious? [] Yes [] No
(The answer is "NO" but it never hurts to hear it from your doctor)
Please explain:

Is Pemphigus or Pemphigoid inherited? [] Yes [] No

If there is a genetic connection, will my children get the disease? [] Yes [] No

DIAGNOSIS

Has an immune fluorescence test been done on the biopsy? [] Yes [] No
If not, will you order one? [] Yes [] No

Will you take a blood test to confirm the presence of antibodies? [] Yes [] No

What will you look for in an antibody test? [] Yes [] No
(1) Antibodies to Desmoglein 1 _____
(2) Antibodies to Desmoglein 3 _____
(3) Other Antibodies _____

When the antibody titer test is done, can you tell me the results? [] Yes [] No

How important is the titer count in treating the disease?

INITIAL TREATMENT

Will the first drug you prescribe for me be a steroid? [] Yes [] No

If yes, how many milligrams are you prescribing? _____

Why are you recommending that particular dosage? _____

When during the day should I take steroids? _____ Morning _____ Afternoon _____ Night

Should I take steroids with food? [] Yes [] No

Studies have shown 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, and high cholesterol. How can I cope with these side effects?

Since you are prescribing steroids, should I have a bone scan?] Yes [] No

If yes, how often? _____

Steroids can cause stomach problems; should I take Pepcid, Zantac, or Tagament? [] Yes [] No

If I am on steroids **only**, how often should I have a blood test? _____

What should we look for in a blood test? _____

Will you also prescribe any of the following?

[] Imuran [] CellCept [] Cytoxan [] Dapsone [] Plaquenil

[] a cycline drug [] niacinamide [] other _____

How many mg will you prescribe? _____ And how often? _____

What are the side effects of these drugs? _____

If I am on immunosuppressive drugs, how often should I have a blood test?

What should we look for in a blood test?

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?

SPECIALIST AND DIETARY HEALTH QUESTIONS

Should I see an Internist or other physician to help me deal with drug side effects? Yes No
Who do you recommend? _____

Certain blood pressure medicines can trigger Pemphigus flare ups. If I need this kind of medication which ones should I avoid?

Are there any foods I should stay away from or avoid?

Do you recommend a specific diet?

Can I go out in the sun? Yes, No

Should I exercise, and if so how much should I do, and how often? Yes, No

Should I consult with an Ophthalmologist? Yes, No
Who do you recommend? _____

Is stress an important factor? _____

Are there any vitamins or supplements I should take? Yes, No
Which ones should I avoid? _____

Should I take Calcium supplements? Yes No
Vitamin D? Yes No

Can I take immune enhancing drugs? Yes, No

The IPPF suggests you keep a diary tracking the course of your disease. This should include the dates of any adverse reactions to medication, your diet, any physical problems you are experiencing, and pictures if possible. This can be useful in planning your course of treatment and sharing your progress/flare ups with your doctors. Learning to live with Pemphigus and Pemphigoid is a process and it takes time and patience. Please feel free to call us, or you may want to consult a counselor or a therapist.

STEROID TREATMENT

Will I be able to taper off of steroids? [] Yes [] No
If Yes, when _____ and by how much? _____ mg

Should I expect to have inflammation or a flare when tapering? [] Yes [] No

What do you recommend if I find that the inflammation is too much to manage?

Can you prescribe the steroids in a smaller mg pill so I can taper slower?

Should I be using topical steroids along with the systemic steroids? [] Yes [] No

OTHER TREATMENT

You are prescribing _____ and my initial dose is _____ mg,
Will you be increasing it later? [] Yes [] No
If Yes, when _____ and by how much? _____

_____ Mg How long does it take for
this medication to begin working? _____

What side effects should I expect? _____

If my condition has not improved by then will you recommend a different medication? If so,
which one and at what dosage? _____, _____ mg

What side effects should I expect from this new medication? _____

How long does it take for this medication to begin working? _____

ORAL DISEASE QUESTIONS

Since I have oral activity should I see a Dentist? [] Yes [] No

Do you know one with experience that you would recommend?

Are there any types of dental procedures that I should avoid? [] Yes [] No

Should I be avoiding or using specific dental/oral products? [] Yes [] No

Would you recommend topical oral steroids? [] Yes [] No

How long does it take for this type of medication to begin working?

Please tell your physician about the IPPF.

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