QUESTIONS TO ASK YOUR DOCTOR

The following questions might be appropriate to ask one's physician when Autoimmune Vasculitis is suspected or diagnosed. The questions were prepared by a Wegener's patient (with no medical training) in July 2005.

Disclaimer:

1. These questions are NOT intended to be presented directly to a physician. The sheer number of questions would likely result in a negative response.

2. They are intended to be used to help the patient or advocate write up 5-10 questions for each upcoming appointment as seems applicable.

3. The background comment (BG) with each question is to help the patient know why the question is appropriate at times.

4. PLEASE NOTE: Patients should NOT submit these questions as written to their physician. The list was created to help patients develop their own questions.

5. Each AV patient must educate themselves about the disease and treatment options for their own protection and effective treatment. Please be sure to state to the physician that you understand he/she may not have the answer right at hand.

The first and most important question to be asked is:
1. "Have you treated many vasculitis patients and what were the outcomes?"
BG - As AVs are rare, it is vital to effective treatment to be examined by persons with adequate experience and training in diagnosing and treating autoimmune vasculitides (AVs).

Initial and Diagnostic Questions
2. Should I be referred to another physician or specialist with considerable experience diagnosing and treating my symptoms?
BG - Most physicians, including most specialists, will not have seen a case of AV in the course of their practice. This means the patient must seek the expertise needed with his/her physician's help. The specialists most likely to have experience with the AV diseases are rheumatologists; so requesting a referral to a rheumatologist is a prudent first step.

3. What types of specialists should I see as part of the diagnostic procedure?
BG - Depending on the specific organs attacked by the AV, various specialists may be involved in the patient's diagnosis and treatment.

4. Once diagnosed, should I get a second opinion from a major medical center or specialist?
BG - It is generally considered good medical practice for most serious medical conditions including AV to get a second opinion by a physician experienced and specializing in the diagnosis and treatment of the disease.

5. Is my condition likely to be caused by an autoimmune vasculitis?
BG - There are vasculitides that are not autoimmune vasculitis. These can be caused by allergies, infections, medications or environmental conditions. It is important to know if the condition is autoimmune or some non-autoimmune vasculitis.

6. If a vasculitis is not autoimmune, what kind do I have?
BG - Hypersensitivity vasculitis or vasculitis as the result of infection are treated differently than an autoimmune vasculitis. It's important to know what kind of non-autoimmune vasculitis one has.

7. If an autoimmune vasculitis, which kind do I have?
BG - There are a variety of related autoimmune vasculitides with varying and sometimes overlapping symptoms, which may be organ specific in their manifestations. It is important to know which specific organs are involved, but may not always be the determining factor in selecting the treatment regimen.

8. What is the severity of my current condition? (Mild, Serious, Grave)
BG - The severity of the patient's condition at diagnosis and the precise organs involved will determine whether a rescue therapy is necessary, and if not, which treatment options are appropriate.

9. What is the usual prognosis for my current condition?
BG - It can ease the patient's concerns if they have some idea of the likely outcome of treatment.

10. What kind of diagnostic tests have you ordered or will be ordered?
BG - It is helpful to the patient to know how many tests of what type and why they are ordered and what times and special preparations will be required of the patient.

11. What baseline tests should be run?
BG - As an AV patient you will be followed carefully, it is important to have a series of baseline tests to establish your initial condition so that later tests will have a basis on which to judge if a particular condition is improving or worsening.

12. Should there be a baseline bone scan?
BG - As most AV patients are on a corticosteroid such as prednisone for long period(s), a baseline bone scan can be important for early detection of osteopenia or osteoporosis.

13. Will I need a biopsy? Of what organ(s) and what is the procedure to be used?
BG - Tissue samples (biopsies) are often used to help define the specific status of the AV in the patient. Some physicians will not treat for AV without a biopsy positive for AV. Physicians with considerable experience treating AV will use their judgment on whether or not to treat as an AV without a positive biopsy. The patient should know what biopsies are ordered, why, and what is involved so that they can be better prepared to understand the need for these procedures and the methods to be used.

14. Could a guided needle biopsy be useful and safer than an open lung biopsy?
BG - The "guided needle biopsy" is minimally invasive and may be satisfactory if a lung, kidney, or other biopsy is required. Surgery to open the chest or abdomen for biopsy of organs is a highly invasive procedure and probably should be avoided if possible. If open cavity surgery is required, the patient needs to understand why and what the risks are.

15. Will my biopsy be sent to at least two pathologists who are not associated in the same practice?
BG - Pathologists have mistaken granulomas for lung cancer and other conditions so that biopsies might well be submitted to two or more independent pathologists for their interpretation of the samples.

16. What kinds of radiograph tests are needed (x-ray, CT scan, MRI, ultrasound, other)?
BG - Some types of AV result in lung or other organ damage, not always detectable by x-ray. It may be prudent to have CT scans, MRIs, or ultra-sound tests to fully determine the extent of the patient's disease. For Central Nervous System (CNS) involvement, a digital subtraction MRA might be appropriate.

17. Will my radiographs be sent to at least two radiologists not associated in the same group practice?
BG - Radiologists have mistaken AV lung damage as lung cancer. It may be prudent to have radiographs submitted to two or more independent radiologists for interpretation.

18. Do I need lung function tests?
BG - Some AVs frequently involve lung damage so baseline lung function tests should be done in cases where lung involvement is known or suspected. Periodic checks should be made at the physician's judgment.

19. Do I need any endoscopic examinations and what is involved?
BG - Endoscopic examination of the pulmonary, upper airway, and G/I tracts may be required to determine the extent of the disease particularly in the cases of Polyarteritis Nodosa, Churg Strauss syndrome and Wegener's granulomatosis. Patients need to understand the procedures in order to not have undue anxiety.

20. Should I be tested for Alpha-1 antitrypsin deficiency?
BG - Alpha-1 antitrypsin deficiency (AATD) has been found in a percentage of AV patients. If an AV is suspected or diagnosed, a test for the level of alpha-1 antitrypsin deficiency may be prudent. AATD causes progressive lung and possibly liver damage if untreated.

21. What further tests are required before I can begin treatment?
BG - Depending on the patient's symptoms, history, and clinical examination results, other tests may be indicated such as hearing, vision, endocrinology functions, adrenal and thyroid functions, etc.

Disease Questions

22. Why did I develop an autoimmune vasculitis?
BG - The exact causes of autoimmune vasculitides are unknown.

23. What are the frequent symptoms of my type of vasculitis?
BG - Each AV has its distinguishing characteristics. The symptoms may vary from patient to patient yet there are patterns of usual organ involvement for each type of AV. The patient should know there is a possibility they may develop some of the more common symptoms than they already have.

24. What are the infrequent symptoms of my vasculitis?
BG - The patient should know the less likely symptoms besides the ones they already exhibit in order that they not be unduly concerned about new symptoms, but promptly report those to their physician

25. Is my vasculitis contagious?
BG - AV patients need to know if their conditions are a danger to others.

26. Is my vasculitis inheritable by my children?
BG - None of the AVs are directly inheritable but it is reassuring to have that clarified by one's physician.

27. Could my disease be caused by medications I'm taking or by environmental exposures?
BG - Some vasculitides are caused by medications, infections, or exposure to unusual elements in the environment, but these are not autoimmune vasculitides. It is important that one not be treated for an AV if the causes of the vasculitis are other than immune system dysfunction.

28. Could I have avoided getting this disease?
BG - Generally speaking, as causes are virtually unknown, the only possible ways known to help avoid AV are avoiding exposure to particulate silica and excessive physical or emotional stress.

29. How frequent is my vasculitis in the general population?
BG - It is well to understand how rare the disease is to appreciate the lack of knowledge and experience with AVs in the medical community.

30. Does having relatives with autoimmune diseases have something to do with my having vasculitis?
BG - Autoimmune diseases tend to run in families so there is apparently a genetic predisposition to autoimmune disease. It may be helpful to close relatives to know one in the family has AV.

31. What are similar kinds of autoimmune vasculitis besides the kind I have?
BG - As symptoms overlap between various AVs, it may be helpful for the patient to know that.

32. Am I more likely than average to have another autoimmune disease?
BG - Persons with one autoimmune disease are at a somewhat greater risk for developing a second autoimmune disease than is the general population. It is good for the patient to understand that in order to identify any newly developed autoimmune disease as early as possible.

33. What are my chances of relapse once the disease is inactive?
BG - The AV patient should know if relapse is likely or unlikely so that so the patient has reasonable expectations and so that new or renewed symptoms can be dealt with promptly.

Treatment Questions
34. How long before I can start treatment?
BG - With possibly serious consequences to delay of treatment, the patient needs to be assured when treatment will begin, and what the treatment will likely be.

35. Who will coordinate between my primary care physician and any specialists involved?
BG - With multiple physicians involved in the patient's care, it is important that each physician be promptly notified of all actions, medications, procedures, and changes in the patient's condition.

36. Should I be hospitalized?
BG - Some AV cases can abruptly endanger organs and the patient's life. In some cases hospitalization is needed to allow procedures and care that can only occur there. It is well that the patient knows that as soon as possible in order prepare mentally and arrange affairs to ease the strain of hospitalization.

37. I currently have an infection of the ________. Does that effect my treatment?
BG - Any infection may restrict the options for treatment of the AV. It is important that the patient's physician know of any infection before and during treatment.

38. How aggressively does my condition need to be treated to stop further damage?
BG - The degree of aggression used to treat the AV is determined by the treating physician. It seems likely that more AV patients suffer from treatment that is inadequate than are harmed by overly aggressive treatment.

39. Do I need to have a test for tuberculosis before starting on an immunosuppressive or steroid?
BG - Immunosuppressives used to treat AVs can permit latent infections to become active. If a patient has been in locations where they might likely have been infected by TB, or has had a positive result from a previous TB test, then that patient must be treated to prevent TB from becoming active.

40. Should I have plasmapheresis treatments? How many?
BG - In highly active AV cases, a rapid improvement may be achieved by removing the harmful antibodies from their blood stream. The treatment can be repeated as necessary.

41. Would intravenous gamma globulin be appropriate treatment?
BG - Gamma globulin has proven effective in treating some AVs but it is not risk free.

42. What short- and long-term side effects can I expect from use of prednisone (or similar steroid)?
BG - Prednisone can have serious short and long-term side effects. The AV patient should learn what these are in order to not be surprised when a side effect appears, and also to be better able to differentiate between a steroid side effect and a symptom of the AV.

43. If I'm on a steroid, should I have calcium supplement, extra vitamin-D, and either a biphosphonate (such as Fosamax or similar) or PTH to prevent osteopenia or osteoporosis?
BG - Even short-term corticosteroids can cause loss of bone mass. That effect can be reversed by use of calcium supplements, extra vitamin D, perhaps supplemental magnesium, and an appropriate medication that stimulates bone growth.

44. Does my condition warrant use of Cytoxan, Cellcept, Imuran or similar broad immuno-suppressive?
BG - While some mild AVs may be treated by steroidal medications alone, many cases require the use of one or more immunosuppressive drugs to stop the overly active immune system from producing too much harmful antibody. The use of powerful broad immunosuppressive agents such as Cytoxan (cyclophosphamide) can have serious side effects, so their use must be carefully weighed.

45. If I will be on an immunosuppressives, at what dosages and for how long?
BG - Immunosuppressives have side effects that usually require some adjustment in your activities. The patient's concerns can be relieved if the patient knows what immunosuppressant will be used and how.

46. If I will be on an immunosuppressive, will it be oral or intravenous?
BG - While there is some controversy, it appears that a daily orally administered immunosuppressive may be more effective than a periodic intravenous injection. The higher risks associated with a daily dosage versus the periodic injection have to be considered when deciding on the treatment regimen.

47. If I'm on an immunosuppressive, what short and long-term side effects are likely?
BG - Powerful broad immunosuppressive agents such as cyclophosphamide can have serious side effects. It will be useful for the patient to know what might be experienced so not to be overly anxious when side effects appear. The patient's physician may suggest ways to ameliorate some side effects.

48. Could one of the biologicals such as Enbrel, Remicade, Humira, or Rituxan be more appropriate instead an immunosuppressive?
BG - There are now a number of "biological" medications that are monoclonal antibodies. These are expensive drugs usually given by injection at weekly or bi-weekly intervals. They are narrow or targeted immunosuppressives that don't attack many types of cells, but rather disable certain harmful cytokines (chemical signals between cells). They can be highly effective with fewer side effects than the non-biological immunosuppressants.

49. Will I be susceptible to opportunistic infections? If so, what prophylactic measures to avoid infection will be appropriate?
BG - Immunosuppression by any means makes a person more susceptible to opportunistic infections.

Disease Tracking Questions

50. How often will I need appointments to see you? How often can I expect blood and urine tests?
BG - Patients may need to arrange for childcare, time off work, or to have an advocate accompany them.

51. How often will I have to have radiographic tests? (X-ray, MRI, CT scan, ultrasound)
BG - Patients may need to adjust their schedules and the schedules of others to allow the necessary tests.

52. Are there other specialists I should routinely be seen by, and how often?
BG - Depending on the organs involved and the severity of the involvement, the patient may need to have scheduled periodic appointments with various specialists.

53. What blood test results should I use as a possible indication of disease activity?
BG - From lab test reports, a patient may sometimes choose to track their own progress toward remission (within the limits of applicability).

54. What urine test results should I use as an indication of kidney dysfunction?
BG - If kidneys are involved in AV, then the patient may well want the assurance of knowing if their kidney function improves or deteriorates.

55. How will I get copies of my lab test results, radiograph reports, and clinical exam reports?
BG - Patients often find it useful to track certain test results to know if progress toward remission is evident.

56. How can I be assured that significant changes in lab or radiograph test results will be not be delayed in reaching you?
BG - It is important the patient has some assurance that the physician will be promptly notified of significant changes in test results, if such results are received by an office employee or transferred by a process involving delay such as U.S. mail.

57. Should I use urine dipsticks at home to test for protein and blood?
BG - Dipsticks are available to test urine at home. Patients need to know if they should use dipsticks and what type to use.

Life Change Questions
58. Will the medications on which I will be effect my fertility?
BG - Some medications used to treat AVs may diminish female or male fertility. Some patients may become infertile as a result. Treatment decisions may be effected by the question of possible sterility.

59. I plan on having children. Are there alternative medications that can effectively treat my autoimmune vasculitis without causing sterility?
BG - Some "biological" medications may be suitable to treat WG without threatening fertility.

60. I'm pregnant. Will my vasculitis endanger the embryo or fetus?
BG - Certainly a major issue where the patient needs to know the possibilities.

61. I'm in my first trimester, what medications, non-prescription medications, and dietary supplements must I avoid?
BG - Some medications, non-prescription medications, and dietary supplements may interact with medications used to treat the AV, or may reduce or enhance the effectiveness of medications used to treat AV.

62. I'm past my first trimester, what medications, non-prescription medications, and dietary supplements must I avoid?
BG - Some of the restrictions on medications, non-prescription medications, and dietary supplements may be lifted after the first trimester.

63. What precautions do I need to take to avoid aggravating my condition?
BG - There may be behaviors, medications, or supplements that are likely to aggravate the AV and are best avoided.

64. Are there things I can do to avoid recurrence of active AV?
BG - The patients need to know what means is within their power to help avoid relapse.

65. What changes in my usual diet do I need to make?
BG - There may be foods to be avoided or a different balance of protein, fats, and carbohydrates that might impact AV activity.

66. Are there vaccinations I should have or shouldn't have?
BG - Certain vaccinations may not be safe. Others may be prudent. Still others may be mandatory.

67. Will I need vitamin or mineral supplements?
BG - Depending on age, disease activity, sex and other factors, physicians may wish to instruct the patients to take vitamin and mineral supplements.

More Life Change Questions
68. Can I drink alcohol during treatment?
BG - Some treatments challenge the liver so that minimal use of alcohol may be indicated or even abstinence.

69. Will I have to change my activities while I'm in treatment?
BG - Because of the disease and medications, it's possible that an AV patient may have to reduce certain activities in order not to aggravate their condition.

70. What over-the-counter medications and dietary supplements must I avoid?
BG - Interactions between medications and dietary supplements may interfere with the treatment of AV.

71. How much exercise should I undertake while in treatment?
BG - Exercise within reasonable limits may be helpful, but never near exhaustion.

72. How is the vasculitis and treatment likely to affect my friends and family?
BG - AV patients should be aware that both the disease and the medications might cause them to behave uncharacteristically. Because AV patients often look well, many will be thought to be less ill than they are in actuality.

73. What should I tell people who ask about my disease or condition in order to not be shunned or left out?
BG - Use of the word immune or autoimmune may trigger the assumption that one has HIV (AIDS). Comparing AV to lupus may help some understand. Simple "inflammation of blood vessels that damages organs" might be enough.

Emergency Questions
74. What particular symptoms should I regard as an emergency?
BG - Certain symptoms are ones requiring rapid medical attention.

75. Under what circumstances should I go the Emergency room at my local hospital
BG - Excessive unnecessary use of emergency facilities is to be avoided, but when in doubt, do go.

76. Under what circumstances do you want me to contact you outside office hours?
BG - Some physicians choose to be notified outside of office hours for specific occurrences.