

Vasculitis and azathioprine

Summaries and decision aid

Information about vasculitis and treatment

What is vasculitis?

Vasculitis is a group of diseases, including Wegener's granulomatosis, Churg–Strauss syndrome, microscopic polyangiitis and polyarteritis nodosa, in which blood vessels are inflamed. The inflammation or swelling can occur anywhere in the body and can cause the walls of blood vessels to thicken, weaken, narrow, scar or break. Blood clots may form and blood may not be able to flow well to the tissues and organs in the body. With a poor blood supply, the tissues may die and organs may not work well. Vasculitis can be mild or more severe and life-threatening.

Some types of vasculitis may occur once and go away on their own, while others will need to be treated. Other types may occur in cycles, where there are flare-ups and then periods with no symptoms (remission). Treatment is used to stop flare-ups and to make sure blood vessels are not damaged. If vasculitis is not treated, inflammation or swelling in blood vessels can lead to permanent damage to tissues or organs and cause:

- loss of vision
- heart attack, kidney failure, lung damage
- gangrene
- death.

What can I do on my own to manage my disease?

✓ exercise when possible ✓ avoid alcohol ✓ rest and relax ✓ dress warmly in cold weather

What treatments are used for vasculitis?

Three kinds of treatment may be used alone or together. The common (generic) names of treatment are shown below:

1. *Oral or IV corticosteroids*

- Prednisone
- Prednisolone
- Methylprednisolone

2. *Immunosuppressive agents (cytotoxics)*

- Azathioprine
- Cyclophosphamide
- Ciclosporin
- Methotrexate

3. *Other therapies*

- Plasma exchange
- Intravenous immunoglobulin

What about other treatments I have heard about?

There is not enough evidence about the effects of some treatments. Other treatments do not work. For example:

- Acupuncture
- Electropuncture
- Ultrasound
- Electrical stimulation
- Thermotherapy

What are my choices? How can I decide?

Treatment for your disease will depend on your condition. You need to know the good points (pros) and the bad points (cons) about each treatment before you can decide.

Vasculitis decision aid:

Should I switch to azathioprine after going into remission with cyclophosphamide?

This guide can help you make decisions about the treatment your doctor is asking you to consider.

It will help you to:

1. Clarify what you need to decide
2. Consider the pros and cons of different choices.
3. Decide what role you want to have in choosing your treatment.
4. Identify what you need to help you make the decision.
5. Plan the next steps.
6. Share your thinking with your doctor.

Step 1: Clarify what you need to decide What is the decision?

Should I continue to take cyclophosphamide or take a different drug (such as azathioprine) after going into remission?

Cyclophosphamide can be taken as a pill or as an infusion into the veins (IV); azathioprine is usually taken as a pill.

When does this decision have to be made? Check one

within days within weeks within months

How far along are you with this decision? Check one

- I have not thought about it yet.
- I am considering the choices
- I am close to making a choice
- I have already made a choice

Step 2: Consider the pros and cons of different choices

What does the research show?

Taking azathioprine after going into remission is classified as: **Likely beneficial**

There is “Silver” level evidence from 1 study of people with vasculitis who stopped taking cyclophosphamide and started another drug after going into remission. These studies found pros and cons that are listed in the chart below.

What do I think of the pros and cons of azathioprine?

1. Review the common pros and cons.
2. Add any other pros and cons that are important to you.
3. Show how important each pro and con is to you by circling from one (*) star if it is a little important to you, to up to five (*****) stars if it is very important to you.

PROS AND CONS OF AZATHIOPRINE TREATMENT	
PROS (number of people affected)	How important is it to you?
Less flare-ups and lower chances of dying than if stopped taking medications for vasculitis	* * * * *
Same number of people had a flare-up of vasculitis in the 18 months after going into remission with azathioprine or cyclophosphamide about 14 out of 100 people had a flare-up	* * * * *
No chances of bladder cancer with azathioprine	* * * * *
Less people have blood in urine 1 out of 100 people with azathioprine have blood in urine 4 out of 100 people with cyclophosphamide have blood in urine	* * * * *
Other pros:	* * * * *
CONS (number of people affected)	How important is it to you?
Side effects: lowers white blood cells in about 55 out of 100 people taking azathioprine or cyclophosphamide	* * * * *
Can cause fever, chills or rash 7 out of 100 people taking azathioprine	* * * * *
Personal cost of medicine	* * * * *
Other cons:	* * * * *

What do you think about taking azathioprine? Check one

- Willing to consider this treatment
 Pros are more important to me than the Cons
- Unsure
- Not willing to consider this treatment
 Cons are more important to me than the Pros

Step 3: Choose the role you want to have in choosing your treatment

Check one

- I prefer to decide on my own after listening to the opinions of others
- I prefer to share the decision with: _____
- I prefer someone else to decide for me, namely: _____

Step 4: Identify what you need to help you make the decision

What I know	Do you know enough about your condition to make a choice?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
	Do you know which options are available to you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
	Do you know the good points (pros) of each option?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
	Do you know the bad points (cons) of each option?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
What's important	Are you clear about which pros are most <i>important to you</i> ?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
	Are you clear about which cons are most <i>important to you</i> ?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
How others help	Do you have enough support from others to make a choice?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
	Are you choosing without pressure from others?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
	Do you have enough advice to make a choice?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
How sure I feel	Are you clear about the best choice for you?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure
	Do you feel sure about what to choose?	<input type="checkbox"/> Yes	<input type="checkbox"/> No	<input type="checkbox"/> Unsure

If you answered No or Unsure to many of these questions, you should talk to your doctor.

Step 5: Plan the next steps

What do you need to do before you make this decision?

For example – talk to your doctor, read more about this treatment or other treatments for vasculitis.

Step 6: Share the information on this form with your doctor

It will help your doctor understand what you think about this treatment.

Decisional Conflict Scale © A O'Connor 1993, Revised 1999.

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