

Brochure - Questions to Ask Your Doctor

Background

You are likely to have a lot of questions following a diagnosis of alpha-1 antitrypsin deficiency (A1AD). You have the right to ask questions, to be informed and to receive information. Select the questions below that best relate to your situation. Some of the questions may be relevant when first diagnosed and again later. It is wise to take your questions to your appointment to ensure that you cover everything. If you have a lot of questions you may like to book a longer appointment. If the questions relate to a loved one, substitute "my" and "I" with their name.



Questions About A1AD, Its Impact and Tests

- What is Alpha-1 antitrypsin deficiency / A1AD?
- How serious is my deficiency / A1AD?
- What is my short-term / long-term prognosis?
- How will my diagnosis affect my home / family, work or social life?
- Should I have a blood test to test my phenotype and genotype?
- What is the cost of tests?
- What other tests should I have?
- When will I know the test's results?
- How often should I be tested?
- What do my test results mean?
- What symptoms should I watch for?
- What diseases do I have / may develop associated with A1AD?

Questions About Treatment / Management

- How many patients have you treated with A1AD?
- Do I need a follow-up visit and if so, when?
- Is there anything that I can do to avoid getting worse?
- What are my treatment options?
- What is the cost of treatment?
- What risks and benefits are associated with treatment?
- What would happen if I didn't have any treatment?
- Is there anything I should avoid during or after treatment?
- What should I do if I have side effects?

- How will I know if my treatment is working?
- What should I do if I forget to take my medication?
- What should I be doing before my next visit?
- What health professionals / specialists do I need to see?
- Does the health professional / specialist work at both public and private hospitals?
- Should I see a genetic counsellor / dietitian / other health professional / go to rehab?
- If I need to be admitted to hospital, how long will I have to wait?

Questions About Surgery

- Why do I need surgery?
- What surgical procedure are you recommending and why?
- How urgent is the procedure?
- What if I delay having the surgery?
- Are there alternatives to surgery?
- How much will surgery cost?
- What are the risks and benefits of having surgery?
- How long will it take me to recover?
- How much experience do you have performing this surgery?
- How long will I be in hospital?

Other Questions to Ask

Where to go for information and support

Alpha-1 Organisation Australia (A1OA): ph: 0450 406 693, email: contactus.a1oa@gmail.com

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This information sheet is one in a series produced by the Alpha-1 Organisation Australia. This information is designed to be a guide only and does not replace advice given by your health professional. Any treatment information or brand names are correct at the time of printing. If the information raises concerns or if you have further questions please consult your doctor.