

## Lesson 3 - Setting treatment goals and building a treatment plan

Lesson 3 of JointHealth™ Education – Ankylosing Spondylitis has the important information you need to use your appointment time with your rheumatologist as effectively as possible to have better conversations and outcomes.

The information in this lesson will also discuss how to identify treatment goals and build a treatment plan in partnership with your rheumatologist.

Please read each section of this lesson carefully, and then when you are ready, take the Lesson 3 Quiz to test your new knowledge. The Quiz is an interactive and printable PDF.



### Time management

- Depending on which country you live in, your appointment time with your rheumatologist can vary from 45 minutes to 1 hour for the first visit, to 15 minutes for a follow up visit. Once you get to know your rheumatologist better, and learn how to get into in a “conversation groove” with them, you should find you have the time necessary to cover all that you and they want during your appointments. *Managing your time is important to getting the most out of each appointment.*
- Your rheumatologist should try to create a safe and non-judgmental environment during the appointment that encourages you to communicate and share your concerns and ideas openly. If they do, they get the information they need to consider how you are doing medically, and also helps you build your confidence in yourself and in your partnership with them.
- *It is important to ask questions that promote discussion between you and your rheumatologist to have good two-way conversation, but keep an eye on your time. Most health care providers want you to keep questions to 2 or 3 per visit because they also need enough time to do their job and fulfill their medical responsibility to you. At every visit, your rheumatologist needs to ask you a short, standard list of questions as well as complete a thorough joint examination. That takes about 5 to 7 minutes.*
- *Some patients with AS think that having longer and more frequent visits with their rheumatologist will lead to better management of their disease. If both you and your rheumatologist manage your appointment well, there should be enough time to discuss your key questions for that visit, as well as have the needed time for a complete joint exam.*



## Asking questions, sharing fears and concerns, and listening

- Patients with AS need to feel comfortable and feel empowered to ask questions. *Being a more educated patient leads to confidence and can result in them taking a more active role in their own AS management.* A more active, involved patient has better disease outcomes. They stick to their treatment plan resulting in overall disease control and health in general.
- Based on new research, many patients with AS think the most common reason linked to good AS management is getting information and having a good discussion with their rheumatologist. *But the majority of patients said they felt uncomfortable raising their concerns and fears with their rheumatologist.*
- *A more engaged, more open patient is more highly regarded by their rheumatologist.*
- Key questions to ask during your appointment depends on what concerns you have at each visit – it will vary. Here is a core set of questions patients with AS commonly ask during their first 2 or 3 appointments. After your third appointment, you should have answers to all of them:
  - What causes AS and is there a cure?
  - What AS signs and symptoms are most common?
  - What parts of the body besides joints does AS affect?
  - Why does AS get worse if it's not treated well or properly?
  - How do I make sure I don't suffer joint damage now or in the future?
  - What types of treatments are effective at controlling AS symptoms and the underlying disease?
  - How soon will my treatment(s) begin to work?
  - How can I tell if they are working?
  - What are the most common medications side effects I should watch for? What happens if the treatment doesn't seem to be working?
  - In addition to taking medication, what else can I do to live better with AS?
  - How do you monitor my disease? Do I need to take regular blood or other tests?
  - How often do I see you?
  - I have a previous back injury due to soft tissue damage. How do I know if this is AS?
  - Am I at a higher risk of developing other diseases as an indirect or direct result of my AS?



## Setting treatment goals

- A treatment goal, is an outcome that you and your rheumatologist aim to achieve through medication and other treatments. For example “I am working with my rheumatologist to control my disease enough so that I can get back to full-time work”
- Setting treatment goals is one of the most important things you and your rheumatologist will do together. *Research shows that rheumatologists say they feel satisfied with their communication with their patients. However, well over half wished they had discussed goals and treatments with their patients.*
- *Research reports that when patients are asked to think about their AS medication(s) in particular, and what treatment success looks like, they say not being in pain anymore and being able to lead a better quality of life.*
- As a patient, it can also be hard to know what treatment success looks like:
  - What sort of treatment goals are realistic and attainable?
  - How much better will I be able to get?
  - Should I set my treatment goals low so that I am not disappointed?
- Although every patient’s disease and circumstances are different, within the last couple decades, treatment has advanced to a point where *now the primary treatment goal for rheumatologists is to help their patients achieve a state of “clinical remission” (when the disease is inactive), or at the very least, low disease activity.*
- *Based on recommendations from a task force of European and North American patients, rheumatologists, dermatologists, and health professionals, new treat-to-target guidelines for spondyloarthritis, which includes ankylosing spondylitis, emphasize the importance to set a target in shared decision making between a specialist and patient and carefully monitor the disease in order to improve a patient’s outcome.*
- *Ankylosing spondylitis patients also feel that getting and exchanging information with their rheumatologist leads to more successful management of their disease.*
- The points above highlight the importance of finding a common language between you and your rheumatologist. For example, rheumatologists need to explain to their patients that the treatment goal they want for you – clinical remission – will also help their patients achieve their goals – no pain and better quality of life.



## Making a treatment plan

- *Research shows that setting treatment goals and making a plan to achieve them results in patients with AS getting better.*
- After you have set treatment goals with your rheumatologist (like, “I want to be in less pain”, or, “I want to get back to full-time work”), you can begin to make a treatment plan.
- *A treatment plan clearly outlines the things you and your rheumatologist will do together to help you (and them) achieve your goals and best manage your AS.* It is usually a written document you create on your computer. Think of it like a “contract” to get better.
- A sample treatment plan for you will include these things:
  - Clearly stated goals (Example: “I love to walk. I want to get back to walking around my neighbourhood so that in 6 months, I can go on a walking vacation with my family.”)
  - A list of steps you will take to reach your goals (Example: “I will create a ‘walking journal’ to track my progress and invite a few people I know who enjoy walking to join me so I don’t have to do it alone.”)
  - Things you think might prevent you from reaching your goals (Example: “Not scheduling the time in my day to get in my walk.”)
  - Things you will measure that will tell you whether you are gradually reaching your goals (Example: When I started walking, I could only do 1 block each day, and after 5 weeks, I can now walk 6 blocks every day.)
  - A list of rewards you will give yourself along the way to motivate you to reach your goals (Example: “When I can walk 6 blocks every day, I’m going to buy myself a new pair of walking shoes.”)