

Lesson 5 - Self-care and ankylosing spondylitis

Lesson 5 of JointHealth™ Education – Ankylosing Spondylitis discusses the importance of what you do in the way of self-care, including learning about what you can and cannot control about your AS.

You will also learn what you can do to maximize the benefits of your treatment plan in between appointments with your rheumatologist. Self-care in AS is a very important aspect of learning to live well with AS.

At the end of Lesson 5, you will understand the importance of self-care principles and actions, know how to develop a daily self-care plan, and learn what aspects of your plan and your progress against it you should share during appointments with your rheumatologist.

Please read each section of this lesson carefully, and then when you are ready, take the Lesson 5 Quiz to test your new knowledge. The Quiz is an interactive and printable PDF.



Take charge of what you can control

- It is important for patients with AS not to blame themselves if a medication or non-medication treatment doesn't work. *There are a number of things about your disease that you can and cannot control, such as which joints the disease will affect, how severe your disease may be at time of diagnosis, whether you will have AS complications, among others.*
- *However, you do control whether you follow the treatments as prescribed and other aspects of your treatment plan that you develop with your rheumatologist.* Recognizing what things in your treatment plan and life that you have control over will give you focus and motivate you to follow through on the things you list in your plan. Patients with AS who follow or “adhere” do better short- and long- term.
- *Key aspects of your self-care plan are:*
 - *Ongoing disease education*
 - *Developing and following healthy life style practices*
 - *Prescription exercise, physical activity and sport for pleasure*
 - *Self-directed, at-home treatments*
 - *Health journaling*
 - *Healthy communication*



Elements of a self-care plan

- *Research has proved that exercise is a vitally important part of your self-care plan. When done safely, even high-intensity exercise is good for patients with AS.*
- The self-care aspects of your overall treatment plan might include things to improve your strength, mobility, and/or flexibility. *Exercise is proved to help improve your AS pain and overall well-being, even if you are currently experiencing pain and fatigue.*
- *There are three general types of AS exercise you can consider including in your treatment plan:*
 - **Range-of-motion exercises:** Joints are moved through as full range of motion as possible to help patients with AS and keep them from losing mobility in affected joints. Range of motion exercises keep your joints moving and reduce pain. It is recommended that these exercises be done daily.
 - **Strengthening exercises:** These help patients with AS to gain muscle mass and increase muscle strength. Strong muscles can help to protect joints. For AS, core strengthening exercises can be particularly beneficial.
 - **Aerobic exercises:** Aerobic exercises include activities like walking, swimming and cycling. These help patients with AS improve heart and lung function, improve strength and reduce pain, and promote self-esteem and self-confidence.
- Ongoing disease education help a patient with AS feel “on top of” their disease and helps to grow their “expertise” leading to greater empowerment and overall feeling of life control. Seeking out evidence-based web sites and resources materials is important to your life-long learning journey.
- Developing healthy lifestyle habits, such as getting appropriate amounts of sleep and rest, taking vitamins and minerals as discussed with your rheumatologist, following a balanced daily diet, quitting smoking if you do smoke, and minimal to moderate alcohol intake, among other self-care behaviours.
- Your daily diet should include appropriate levels of calcium and vitamin D.
 - Calcium and vitamin D supplements can be particularly beneficial for people with AS, as a way to care for their bones, and reduce the possibility of developing a fused spine. A fused spine may increase the risk of fractures.
 - Speaking to a dietician with knowledge about the dietary needs of people with AS is also very helpful. Some dietician services are provided for free. Ask your rheumatologist’s office staff if they can recommend one.

- If you are overweight, losing weight through a balanced diet and exercise may help reduce the severity of your arthritis. This is because being overweight puts extra stress on weight bearing joints.
- Managing your stress levels, getting enough rest, and relaxation lead to a higher quality of life with AS.
- Patients with AS should also pay attention to any irritation, or unusual sensations in their eyes. Some people with AS develop iritis (eye inflammation). If you experience headaches, blurred vision or sensitivity to light, you should see an ophthalmologist (eye specialist).



At home self-care treatments

- There are a number of “at home” treatments available to you to manage the day-to-day symptoms you may have to deal with before your treatment plan begins to work at full steam.
- Ice and heat are your friends, especially in your early days of the disease.
 - Ice applied to hot and swollen joints feels good and helps to temporarily reduce inflammation, helping you better recover from exercise sessions. It is important to have a protective barrier between the ice and the skin (i.e. paper towel, or thin cloth).
 - Apply moist hot towels on non-inflamed, stiff joints to get ready for activities or exercise.
 - Hot and cold baths also help relieve symptoms of joint stiffness and pain.
- Physiotherapy and occupational therapy are helpful and can typically be arranged through your rheumatologist’s office. If your government or private health care plan does not provide coverage for these services, ask your rheumatologist what types of things they might do for you, such as joint protection techniques, stretching or strengthening, that you might be able to safely do on your own.
- For people with AS, good posture is particularly important. Try to be aware of your posture, and keep your spine as straight as possible when doing activities like using the computer, watching TV, or eating food. Core strengthening exercises can also help improve posture.
- In order to protect the spine, patients should avoid activities involving constant bending or heavy lifting when possible



Caring for your mental health

- It is not uncommon for people to experience emotional distress as a result of living with AS.
- For individuals with arthritis, mental health issues can interact with other health conditions and symptoms of arthritis (i.e. pain, fatigue, disability) such that a decline in one area can directly or indirectly affect the others. For example, pain may feel more severe when an individual is experiencing emotional distress, or vice versa, making it even more important to properly treat mental health symptoms.
- There are many self-care strategies shown to improve mental health that you may find useful:
 - Express your emotions in a way that feels safe such as talking to others, artwork or journaling.
 - When possible, exercise and eat healthy.
 - Try to have a regular sleep schedule with about 8 hours of sleep a night.
 - Consider exploring new hobbies or passions to replace activities you may have lost.
 - Take time for yourself, to do things you enjoy, this could even be reading or taking a long bath.
 - Try daily breathing exercises, meditation or mindfulness. Mindfulness can be practiced by paying close attention to events as they occur in a dispassionate, or non-emotional way.
 - Consider joining a support group where you can speak with others who can relate to your experience with inflammatory arthritis or mental health issues.
- If feelings of emotional distress, depression or anxiety persist, it is important to speak to your doctor and seek a referral to a social worker or psychologist.



Sharing your self-care success with your rheumatologist

- *As mentioned earlier in the course, keeping a disease journal is proved to help patients better manage the “details” of AS.*
- *Which aspects of your progress in between visits you need to share with your rheumatologist (and family and friends if you choose) include:*
 - *An accurate record of prescription medication taking*
 - *Symptoms activity, such as joint pain and stiffness and general feeling of wellness (or fatigue)*



- *Improvement or limitations in your daily activities, at home and at work*
- *Questions about changes or additions you would like to make to your treatment goals or treatment plan*
- *New concerns or fears you may have since your last appointment*