



## ANKYLOSING SPONDYLITIS (AS)

**Disclaimer: This course is intended for reference and educational purposes. The information provided in this course should not be used for diagnosing or treating a health problem or disease and should not be used as a substitute for professional care.**

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## Introduction

Welcome to the Ankylosing Spondylitis (AS) eLearning course!

This eLearning course is for people who have been newly diagnosed with AS and people with AS who want to learn more about their condition or their family and caregivers. This course will:

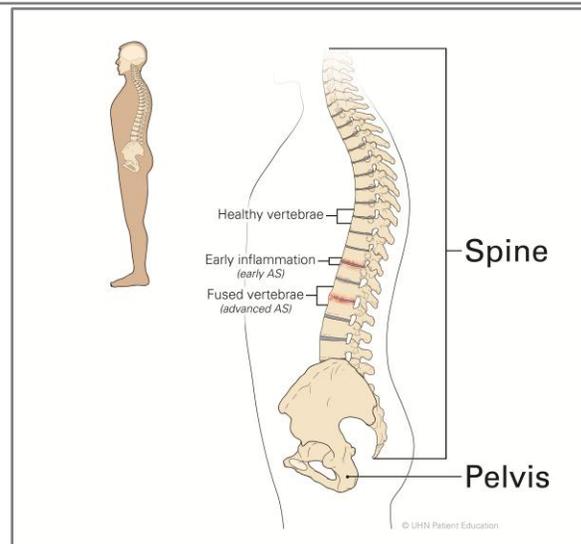
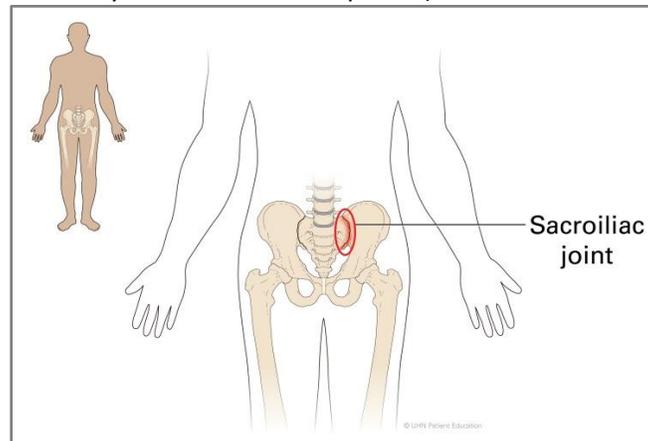
- Provide you with information about the diagnosis and treatment of AS
- Help you understand and learn ways to manage the condition

## Section 1: About AS

### What is Ankylosing Spondylitis (AS)?

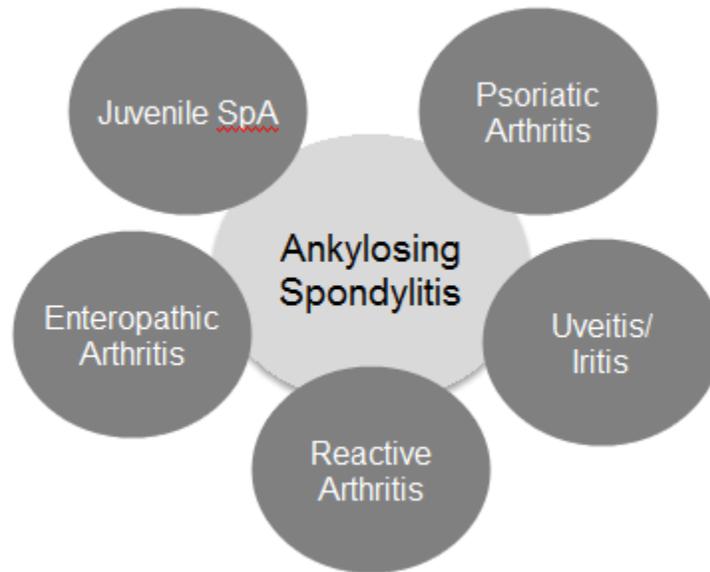
Ankylosing spondylitis (AS) is a type of inflammatory arthritis that affects the spine. It is an autoimmune disease.

Ankylosing means fusing together. Spondylitis means inflammation of the bones of the back. In some AS patients, the joints and bones of the spine may fuse together but it's unusual for the spine to fuse completely. Many people will only have fusion in the pelvis (known as the sacroiliac joints).



AS is a member of a family of diseases that occur in the spine. These are named spondyloarthritis (SpA) and include ankylosing spondylitis, reactive arthritis, psoriatic arthritis, and enteropathic arthritis.

Spondyloarthritis can affect the spine, joints, tendons, ligaments and sometimes the eyes and internal organs.



### ***Enteropathic Arthritis***

Enteropathic arthritis is arthritis associated with inflammatory bowel disease (Crohn's Disease or Ulcerative Colitis).

### ***Reactive Arthritis***

Reactive arthritis is classified as an autoimmune condition that develops in response to an infection in another part of the body.

### ***Psoriatic Arthritis***

Psoriatic arthritis is a form of inflammatory arthritis usually affecting fingers and toes and associated with psoriasis.

### ***Uveitis/Iritis***

Uveitis/Iritis is an inflammation of the uvea or the pigmented area of the eye.

### ***Juvenile SpA***

Juvenile SpA is arthritis that begins in childhood that involves joints along the spine, hips, shoulders, knees, and ankles.

## HLA B27 Gene

We know that Ankylosing Spondylitis (AS) is strongly linked with a gene called HLA B27. HLA B27 is more common in some ethnicities and geographic places. For example:

- First Nations and northern Europeans have a higher incidence of the gene.
- Most people who are HLA B27 positive will never develop AS.
- If you are HLA B27 positive and have children, there is a low chance your children will develop AS.

**Only 7-8% of the general population will have this gene. 95% of patients with AS have the gene.**

## Who Can Get Ankylosing Spondylitis (AS)?

- Throughout North America, about 1 to 2% of people have been diagnosed with AS.
- Generally, AS affects more men than women: For every 3 men diagnosed with AS, 1 woman is diagnosed.
- People with psoriasis, Crohn's disease, ulcerative colitis and uveitis have a higher chance of developing AS than the general population.
- On average, people are less than 40 years of age when they first notice symptoms.
- There are many factors that contribute to developing AS, but up to now, researchers have not found one thing alone that causes it.

## What is the Outcome of Ankylosing Spondylitis (AS)?

- The aim of treating AS involves managing symptoms and improving quality of life.
- There is no cure for AS yet.
- Everyone experiences a different set of symptoms.

Smoking	Smoking increases the risk of spinal fusion.
Gender	Men tend to have more irregular bone growth.
Inflammation	Consistently high levels of inflammation in the blood can lead to changes in bone growth.
Delay in Diagnosis/Treatment	A delay in diagnosis and/or treatment may lead to increased pain, fatigue, and less flexibility.

## Section 2: Symptoms and Diagnosis

### Symptoms

Most people with Ankylosing Spondylitis (AS) find that there are times when their symptoms get worse (flares) and then get better for a short time (remissions). Some people with AS have few symptoms whereas others have more severe symptoms.

### Back Pain

The symptoms of AS usually start under the age of 40 years.

- It begins with back pain which develops gradually.
- The back pain is typically worse in the early morning with stiffness in the back.
- The pain may wake you in the second half of the night and gets better with exercise. It is not relieved by rest.

### *Fatigue*

Fatigue (feeling tired) is common.

### *Joints*

Some people may have pain in the hip and/or knee joints and sometimes in the elbow and/or shoulder joints.

### *Ligaments or Tendons*

Areas of the body where ligaments or tendons attach to bone may become tender and inflamed (this is known as Enthesitis). For example, this may happen around the heel or chest.

## **Diagnosis**

There is no one test that can diagnose Ankylosing Spondylitis (AS). Rather, a diagnosis is made based on your:

- Health history
- A full body check-up
- Blood tests
- X-rays
- MRI (in some instances)

The test results will help decide what treatments are best for you.

## **Section 3: Treatment**

### **Treatment**

#### *Health Care Provider*

Managing AS well happens when you and your healthcare provider work together. Partnering together, you can both reduce the symptoms and improve your quality of life.

#### *Patient*

Education, exercise, physiotherapy, patient and self-help groups are very important to managing AS, along with medical and surgical intervention.

### **Exercise and Physiotherapy**

Exercise and physiotherapy is an essential element of any Ankylosing Spondylitis (AS) management program. It can improve mobility, strength, function and quality of life. It can also help reduce spinal abnormalities, pain, fatigue and depression.

Some patients say they benefit from therapies such as massage therapy, chiropractic treatment, acupuncture and other complementary therapies. Most have not been researched well enough to assess how effective they are. Talk to your health care team about complementary therapy that you are planning to do.

## Medication

There are a series of medications that can be used to control the symptoms and slow down the progression of AS.

In a minority of patients, surgery may be considered if there is severe arthritis of a joint (most commonly the hip) or severe curvature of the spine.

### *Anti-Inflammatory Medication*

NSAIDs (Non-steroidal anti-inflammatory drug) are a class of drugs that reduce inflammation and swelling and provide pain relief.

In rare cases, people with AS may develop inflammation in the joints of the arms and/or legs. In these cases, other drugs known as Disease-Modifying Anti-Rheumatic Drugs (DMARDs) such as sulphasalazine or methotrexate may be used in addition to NSAIDs and/or TNF-alpha blocker.

Occasionally, people with AS who develop severe swelling in the joints of the arms and/or legs will require a local injection of an anti-inflammatory called a corticosteroid.

### *Pain Medication*

Pain relief medications can help to manage AS symptoms. They include analgesics or painkillers, and are any member of the group of drugs used to control symptoms and relieve the pain of AS.

### *Biologics*

Another group of medications known as biologics (TNF-alpha blockers) can also help manage the symptoms associated with AS and have recently been shown to slow down the disease.

If you choose to begin managing your AS with biologics, a nurse with specialized knowledge of biologics will help you begin your treatment. He or she will also discuss with you how your biologic treatment will be covered by insurance (private or government) that best meets your own situation.

## Section 4: Managing AS

### How Can I Manage AS?

There are many factors that affect how you can cope with your condition. Using this e-learning module will help you gain the knowledge, skills and confidence to take charge of your health. We call this “self-management.” Explore some of the factors listed below and learn how you can modify your lifestyle and make healthy choices.

### Managing Pain

Everyone’s experience of pain is different.

- It can affect different parts of the body (e.g. spine, joints, tendons).
- It may occur for many reasons (such as joint damage from before, new inflammation).
- It can be helped by using different strategies, other than medication.

## What Do I Do When My Symptoms Flare?

Most people with AS find that there are times when their symptoms are worse. This is called a **flare**. When you experience a flare, it's important to:

- Use medication as instructed.
- Keep doing all your activities (including everyday activities and exercise) within your pain tolerance. Gentle exercise and moderate activity can help to reduce pain and keep you back and affected joints flexible.
- Rest frequently.
- Contact your health care provider if your flare gets worse, so tests can be done (including the 'BASDAI questionnaire, blood tests (ESR and CRP) and flexibility measurements) to see how best to manage your symptoms.

## Employment

- The majority of people with AS are able to work and be productive in the workplace.
- If you are having a flare, you may need to modify the time you work during the day or week, and the tasks you do while working.
- The Arthritis Society provides tips on how to manage your AS in the work place.

## Exercise

Exercise and good posture can improve mobility, strength, function and quality of life. Exercise can help reduce spinal abnormalities, pain, fatigue and depression. A regular exercise program improves symptoms and maintaining good posture.

Swimming, tai chi, yoga, pilates, cycling and brisk walking are great ways to exercise if you have AS.

## Posture

Imagine a straight line that travels through your ear, shoulder, hip, knee, and ankle.

Good posture is the key to strength, flexibility and function. In some cases, people with AS have fused vertebrae of the neck and/or back. In the past, this resulted in a hunched posture, with good postural training, you can have a normal posture, even with a fused spine.



## ***Stretching***

Stretching exercises can help with pain and stiffness.

- When you stretch, you should take the stretch just to the point of discomfort. You should not experience pain when stretching.
- Go slow. Hold for 15-20 seconds each.
- Do not bounce when stretching.
- Remember to BREATHE!

## ***Strengthening***

Strengthening exercises can help build and maintain a good posture.

- Make sure you have the right posture.
- Start with easier exercises and then do more advanced exercises.
- Try to find group activities.

## ***Exercise Warning***

Before you begin your AS exercise program, you should check with your health care provider (family physician, rheumatologist or physiotherapist) to ensure it is safe to start a new exercise program, especially if you have or had any of the following:

- Cardiac disease
- Respiratory disease
- High blood pressure
- Joint replacement surgery
- Spinal surgery
- Any other medical condition

If you are pregnant, experiencing a flare of your AS, or are not used to exercise it is important to check with your health care provider before starting your exercise program.

If you are beginning to exercise for the first time, or if it has been a while since you have participated in regular exercise, expect some mild muscle discomfort. This is normal and should resolve within hours or a few days after starting your exercise program. If your discomfort persists for more than 3 days and is not improving, hold off on your exercise routine and contact your health care provider.

## ***Fatigue***

Fatigue is a common symptom of AS.

- It can last for days or weeks and is not necessarily relieved by sleep or rest.
- It can be caused by anemia, sleep disturbances, side effects of medications used to treat AS, muscle weakness and inflammation.

Energy conservation can help manage your fatigue. Energy conservation is pacing yourself so that you store your energy and don't get exhausted.

## Techniques to Promote Energy Conservation

### *1. Exercise*

Exercise helps to reduce moderate levels of fatigue. Your physiotherapist can prescribe an exercise program that is good for you.

### *2. Diet*

Overeating, under eating or eating the wrong things can all lead to fatigue. Ask a registered dietician for help if you are worried about your eating habits, or getting healthy foods.

### *3. Rest*

People need different amounts of sleep. It is important to figure out how much and when you need to rest. Do things for yourself that help your body and mind relax.

### *4. Time Management*

Give yourself time to plan your day in a way that helps you to do the most important things while also giving yourself for some down time. Keep in mind the times of day when you have the most and least energy?

### *5. Sleep*

Develop a 'going to bed' routine. This lets your body know that you are preparing it for sleep and encourages your mind to slow down and relax. TV, video games, or other internet activities can stimulate you. Be aware of how they affect you if you do these at night before trying to sleep.

### *6. Setting Boundaries*

Sometimes you need to say 'No, I cannot do this today.' Try not to take on more than you know you should.

### *7. Self-Talk*

Remind yourself that you are doing your best. Some days will be harder than others, but each new day is a chance to adjust your goals.

### *8. Engage in a Variety of Meaningful Activities*

Be sure to put time and energy into activities you enjoy. This will give you more energy to deal with the tasks you may not enjoy so much.

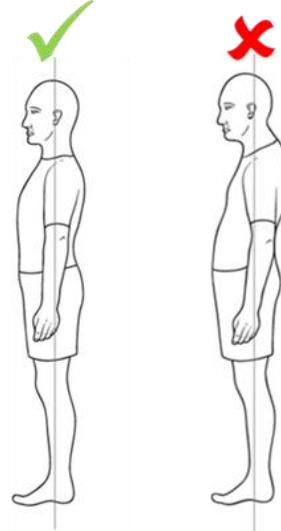
## Activities of Daily Living

Activities of Daily living (ADL's) are the everyday activities we all do. Pay special attention to your posture and try not to hunch forward. Correct and change your posture about every 30 minutes. This prevents muscles from getting too tired and puts less stress on your joints.

Contact an Occupational Therapist for more information about environmental changes at home and at work.

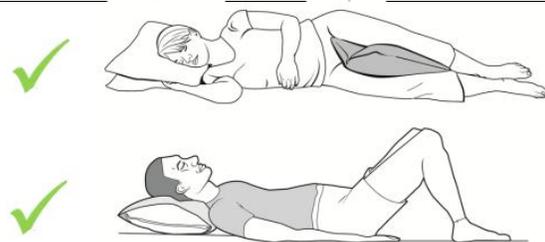
### ***Standing and Walking***

When you need to stand for long periods of time, use a footrest or other raised object to rest your foot on. Alternate your feet. If you are able, push your pelvis forward for a few minutes at a time. Keep an upright posture when walking, with shoulders back. These adjustments can ease the pressure on the lower back.



### ***Sleep Position***

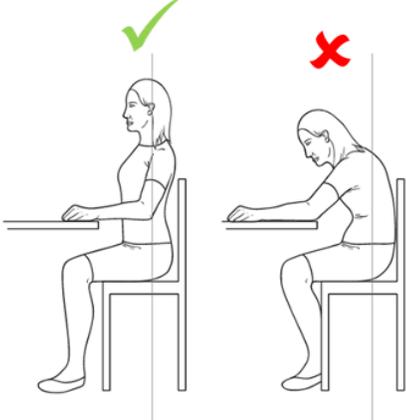
If you have neck involvement, it is best to avoid sleeping on your stomach as this puts more strain on the spine. You may want to try using a special contoured pillow to give you better neck support. Generally, a firm mattress will provide better support. However, it is best to try a mattress for comfort before you buy it.



### ***Bathing and Washing***

Washing at the sink puts more stress on the back than showering because you are bending forward. If possible, put a stool at the sink to reduce the amount of bending required and to ease the strain on the low back. Try to remember to stand straight when you are able to; for example, when you are brushing your teeth. You can buy assistive devices if you have trouble showering or bathing.



<p><b>Dressing</b></p> <p>If you have good flexibility at the hips, bring your feet to your body to put on lower body clothes, socks and shoes. You can buy equipment available to help with dressing, including elastic shoe laces, long handled shoe horns, and velcro to replace fastenings.</p>	
<p><b>Optimal Sitting Position</b></p> <p>Sit in a firm chair with good back support and your hips and knees bent at 90 degrees. A foot support and a chair with contoured back and lumbar support may help if the chair is too high.</p>	

## Diet and Nutrition

### It is important to eat a well-balanced diet.

1. Eat at least 3 to 4 times a day. Three meals a day and snacks in between help us meet our energy needs for everyday activity.
2. Canada's Food Guide describes the amount and types of food that make up a healthy diet. It lets you enjoy the foods you like and gives your body enough vitamins and minerals to keep a healthy weight.
3. Drink 6-8 glasses of water a day to meet your fluid needs. Keeping hydrated is very important for you. It helps your body to work properly.
4. A Registered Dietitian can help with your diet to make sure you meet your nutritional needs.

### Maintain a healthy weight.

This is especially important for people with AS. Being overweight puts increased pressure on the spine and weight-bearing joints and can increase pain.

### Special Diets

Some patients tell us that certain diets help their symptoms (such as Mediterranean diet, low starch diet). These have not been studied very well in AS. Having reduced symptoms may have more to do with changes in lifestyle and weight loss.

While most diets will not be harmful, talk with your health care team about any changes you plan to make. Not eating dairy products may leave your diet low in calcium. People with AS need calcium for healthy bones.

### ***Medication and Diet***

NSAIDs can sometimes cause stomach irritation such as abdominal pain, ulcers or in rare cases, bleeding. Take them with food and see your doctor if you get abdominal pain. A medication can be prescribed to protect the stomach.

### ***Help for Eating Well***

Ask for a referral with a dietitian for one to one appointment.

The Dietitians of Canada's eaTracker helps you set food and activity goals and compare your food choices to Canada's Food Guide.

<http://www.eatracker.ca/>

EATRRIGHT ONTARIO

1-877-510-5102

This is a service for all Ontario residents.

## **Smoking**

Smoking has been shown to make AS worse.

Smoking can affect proper lung function, which may already be decreased due to impaired chest expansion.

## **Emotions**

Having a chronic condition can cause many feelings such as anger, frustration and hopelessness.

Strong emotions can be managed by:

- Recognizing or admitting that you are experiencing strong emotions
- Identifying the source or cause of the emotions
- Developing a response to the emotions
- Learning strategies to address or prevent them in the future

## **Stress Reduction**

It is normal to have some stress each day. Stress is a way that we react to everyday challenges. However, long-term stress can prevent you from managing your daily activities and taking pleasure in them.

Recognize the physical signs and symptoms of stress, including:

- Headaches
- Fatigue
- Upset stomach
- Muscle tension and pain
- Insomnia
- Changes in appetite

- Sexual dysfunction
- Frequent colds or flu

## Depression

Depression is more common in people with chronic conditions such as AS. Depression may cause:

- Fatigue
- Irritability
- Loss of interest in work or hobbies
- Poor sleep
- Low mood

Depression is a treatable disease and, if you are worried about symptoms, discuss these with your health care team.

For support or more information contact the Mental Health Helpline at 1-866-531-2600.

<http://www.mentalhealthhelpline.ca/>

## Relationship Issues and Sexuality

You may notice that having AS affects your relationships, particularly your intimate relationships.

### *How Do You Know?*

- You may feel down or depressed.
- You may feel too tired to engage in activities you once enjoyed, and to have sex with a partner.
- Certain sexual positions may be difficult or painful on your spine and pelvis.
- Negative feelings about your body can cause you to feel uncomfortable or embarrassed in intimate situations.
- Your sex drive may be lowered, partly related to the above issues, and perhaps also related to medication side effects.
- Low libido and infrequent sexual activity can put a significant strain intimate relationships.

### *What Can You Do?*

- **Conserve energy and manage your fatigue:** Use strategies described in this module.
- **Do regular exercise** to lift your mood, control your weight, manage your fatigue, improve your feelings about your body, and boost your libido.
- **Work on communicating openly with your partner:** Poor communication can be a major cause of distress in couple relationships. There are many self-help books and online resources that can help you to communicate more effectively. At times it may help to get advice from a trained professional (such as a therapist)
- **Experiment with various sexual positions** and choose those that cause you the least pain or discomfort. Many find laying on your back is most comfortable.
- **Consider trying a sex toy.** There are many adult sex toys that can provide intense pleasurable sensations, while conserving energy and decreasing fatigue.
- **Consult with your doctor** to discuss your mood, your pain, and your particular sexual concerns. Come with a list of questions, and try to be as open and honest as possible. Some medications may have sexual side effects. It may be possible for your doctor to adjust your medication so that you have fewer (or no) sexual effects.

## Pregnancy

### *Fertility*

AS does not affect male or female fertility.

### *Pregnancy*

AS has no harmful effects on pregnancy or the well-being of the fetus.

Spinal symptoms may flare during pregnancy, partly due to having more stress on the spine and pelvis.

### *Medication in Pregnancy and Breastfeeding*

- If possible, you should plan your pregnancy after discussion with your doctor.
- Some drugs can be continued safely in pregnancy and while breastfeeding.
- Some drugs must be stopped several months before conception (e.g. methotrexate).
- Biologic drugs have not been well studied during pregnancy, but there are many reports of patients continuing their biologic therapy without adverse effects.
- In general, anti-inflammatories can be continued in the first and second trimester and should be stopped at the beginning of the third trimester.
- Decisions about treatment during pregnancy depend on your specific case. Treatment will depend on the risks and benefits in each case and the patient's own preference.
- MotherRisk is an online resource and helpline that provides information on medications in pregnancy and breastfeeding.

## Summary

Many people with AS can live a full and rewarding life. It may be challenging at times. Asking for help and learning to manage AS will greatly help to improve your quality of life.

### Understand your condition

- Explore treatment options
- Use reliable sources of information

### Work with your health care team

- Ask questions
- Share information

### Learn to manage your symptoms

- Discuss your symptoms and strategies for management with your health care team

### Seek support

- Ask for help or join a self-management or support group
- Rely on supportive people in your life

**Please contact (416) 603-5800 Ext.5539 for more information about this eLearning course.**

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## Glossary

### *Anemia*

Anemia is a condition caused by low red blood cells or of hemoglobin in the blood, resulting in weariness and pale appearance.

### *Autoimmune Disease*

An autoimmune disease or disorder is any of a large group of diseases that causes your immune system to “attack” (produce antibodies) your own healthy tissues.

### *C-Reactive Protein (CRP)*

C-Reactive Protein (CRP) is a protein found in the blood and levels rise as a response to inflammation.

### *Crohn's Disease*

Crohn's disease is a chronic inflammatory disease of the bowel and intestines (usually involves the colon and ileum).

### *Enteropathic Arthritis*

Enteropathic arthritis is arthritis associated with inflammatory bowel disease (Crohn's Disease or Ulcerative Colitis).

### *Enthesitis*

Enthesitis is an inflammation of the entheses (the connective tissue between tendon or ligament and bone).

### *Erythrocyte Sedimentation Rate (ESR)*

Erythrocyte Sedimentation Rate (ESR) is a test that indicates how much inflammation is in the body.

### *HLA B27*

Human leukocyte antigen B27 (HLA B27) are proteins that help the body's immune system tell the difference between its own cells and foreign, harmful substances. A blood test is done to look for a protein that is found on the surface of white blood cells. A negative result means HLA B27 is absent and a positive test means HLA-B27 is present. If you test positive for this gene, you have a greater-than-average risk for developing or having certain autoimmune disorders.

### *Internal Organs*

Internal organs are main organs that are situated inside the body, such as the liver or kidneys.

### *Iritis*

Iritis is an inflammation of the iris of the eye (part of the uvea).

### *Joints*

Joints are the place where two bones meet.

### *Juvenile SpA*

Juvenile SpA is arthritis that begins in childhood that involves joints along the spine, hips, shoulders, knees, and ankles.

### ***Ligaments***

Ligaments are flexible cords or bands of fibrous tissues that connects two bones together.

### ***Psoriasis***

Psoriasis is a chronic skin condition that is characterized by red, itchy, scaly patches often on the knees and elbows.

### ***Psoriatic Arthritis***

Psoriatic arthritis is a form of inflammatory arthritis usually affecting fingers and toes and associated with psoriasis.

### ***Reactive Arthritis***

Reactive arthritis is classified as an autoimmune condition that develops in response to an infection in another part of the body.

### ***Spinal Abnormalities***

Spinal abnormalities are differences in normal spine anatomy.

### ***Spine***

The spine is a series of bones (vertebrae) extending from the skull to the small of the back, enclosing the spinal cord and providing support for the chest and abdomen.

### ***Tendons***

Tendons are a flexible cord or band of fibrous tissues that attaches muscles to bones.

### ***Tumour Necrosis Factor (TNF)***

Tumour Necrosis Factor (TNF) is a protein normally present in the blood, but is increased during inflammation and can contribute to joint damage and to pain.

### ***Ulcerative Colitis***

Ulcerative colitis is a chronic inflammatory disease of the inner lining of the gut (usually involves the colon or rectum).

### ***Uveitis***

Uveitis is an inflammation of the uvea or the pigmented area of the eye.