Living with a Chronic Disease – The Story of Ankylosing Spondylitis

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Section 1 Background to AS

1.1 What is Ankylosing Spondylitis (AS)?

Ankylosing spondylitis is a complex, and systemic inflammatory rheumatic disease mainly affecting the axial skeleton, with the potential to cause severe debilitation (Khan 2003). Fibrosis and ossification of tendon, ligament and capsule insertion at the area of intervertebral and sacroiliac discs are the main characteristics of AS (Hakim and Clunie 2002).
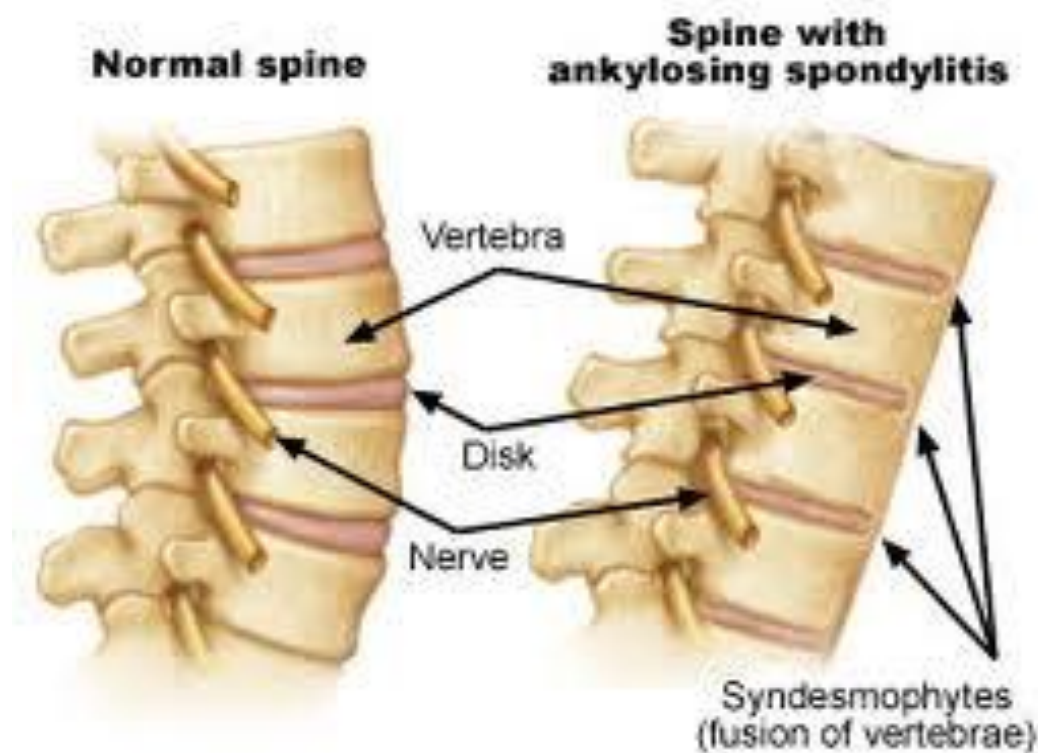
1.2 Pathophysiology

The pathophysiology of AS remains largely unknown. Despite developments into the understanding of this area, it is not possible to link them into a unified theory on pathophysiology; however, it is believed AS is influenced by genetic, environmental and immunologic factors (White 2012).

It is estimated that approximately 90% of the risk of developing AS is related to genetic makeup. Human leucocyte antigen (HLA) B27 and AS show the strongest association of all

rheumatic diseases linked to genetic markers (Pham *et al* 2008). A recent meta-analysis of linkage studies stated that the strongest link occurred with the major histocompatability complex (MHC) region on the short arm of chromosome 6 (Carter *et al* 2007).

Interaction between HLA-B27 and the T-cell response has been cited as a key factor in the pathogenesis of ankylosing spondylitis (AS) (Sieper 2009). Tumor necrosis factor (TNF)-α and interleukin 1 (IL-1) are thought to play a role in the inflammatory reactions observed with the disease (Gorman 2002). Increased T-cell and macrophage concentrations as well as enhanced expression of pro-inflammatory cytokines, including TNF-α, are characteristic findings.

The inflammatory reactions are responsible for distinguishing characteristics of the disease. This includes the enthesis, which is the site of major histologic changes. This begins with a destructive enthesopathy followed by a healing process with new bone formation, linking deeper bone to the ligament and ultimately resulting in bony ankylosis. Typically, vertebral changes begin with an erosive lesion at the anterior annulus fibrosis. The healing process results in increased bone formation, which is initially laid down as cancellous bone, which is then remodeled into mature lamellar bone creating the typical syndesmophytes that are seen on radiography of the spine (White 2012).

Research demonstrates there may be a link between AS and a specific bacterial agent Klebsiella, which has an established relationship to HLA-B27. There may be a role for this agent in initiating or maintaining disease activity (Rashid and Ebringer 2007).

Glossary of Terms:

HLA-B27 (Human Leukocyte antigen- B27): Proteins on the surface of leukocytes and other nucleated cells. These proteins help the body's immune system to recognise its own cells and to differentiate between its own cells and foreign substances.

TNF- α (Tumor Necrosis Factor- alpha): It is a cytokine involved in systemic inflammation. It stimulates and activates the immune system. It can induce inflammation to promote recovery.

IL-1 (Interleukin 1): Responsible for the production of inflammation, and for the promotion of fever and sepsis. It plays a central role in the regulation of the immune responses.

Klebsiella: Gram negative bacteria which can cause infections.

Major Histocompatability Complex (MHC): A cluster of genes located on chromosome 6 concerned with antigen production and critical to the success of transplantation. The MHC includes the human leukocyte antigen (HLA) genes.

Enthesitis

Enthesitis involves inflammation of ligaments, tendons and joint capsules at the point of their insertion to the bone. Enthesitis is a principal feature of the spondyloarthropathies and is considered to be a primary clinical feature of AS (Aydin *et al* 2009). Research has proposed that the primary site of immunopathology is the entheseal fibrocartilage and also the cartilage in general at the interphase with bone (Sieper *et al* 2002).

The Maastricht AS Enthesitis Score (MASES) (Heuft-Dorenbosch *et al* 2003)
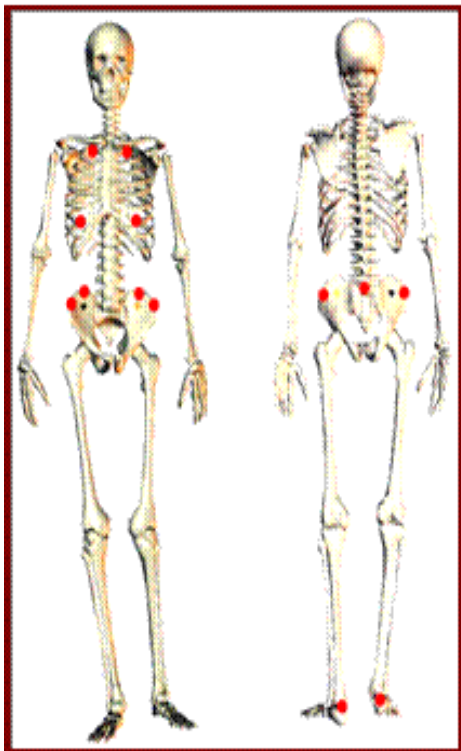
Above is an example of an enthesitis index. There are seven common sites for enthesitis in AS:

1. Iliac crest (Right & Left)
2. PSIS (Right & Left)
3. L5 spinous process
4. Achilles tendon insertion (Right & Left)
5. 1st chostochondral junction (Right & Left)
6. 7th chostochondral junction (Right & Left)
7. ASIS (Right & Left)

This scale has a scoring range of 0 (no point tenderness) to 13 (Maximal score all points tender) based on tenderness on palpation of these seven common sites.

Other examples of enthesitis indices are: the Mander Enthesitis Index (MEI), Spondyloarthritis Research Consortium of Canada Enthesitis Index (SPARCC) and the Leeds Enthesitis Index (LEI) (Coates & Helliwell 2010).

Inflammation may occur at any of the above mentioned enthuses but enthesitis at the heel is reported to be the most common site involving the attachment of the Achilles tendon and plantar fascia to the calcaneus (Dziedzic and Hammond 2010).

Management of Enthesitis

Diagnosis of enthesitis is made via ultrasound as physical examination is not sufficient (Balint *et al* 2002).

Treatment options for enthesitis are limited regardless of its clinical importance. Treatment generally centres on NSAIDs, local steroid injections (not with Achilles tendon due to high risk of tendon rupture), orthoses and anti-TNF-alpha therapy. Anti-TNF-alpha therapy has been shown to be effective at decreasing signs of enthesitis after two months, as monitored by ultrasound (Aydin *et al* 2009). Diagnosis of enthesitis is made via ultrasound as physical examination is not sufficient (Balint *et al* 2002). Neither sulfasalizine nor methotrexate are efficacious in the management of AS (La Salle and Deodhar 2007).

There is speculation that treating foot biomechanics may assist in the management of enthesitis involving the plantar fascia and Achilles tendon. This would involve altering alignment of the rearfoot and controlling foot pronation so as to reduce the risk of increased vulnerability to injury of the entheses. However, further research to support this theory is required as data to support it is currently lacking (Dziedzic and Hammond 2010)

1.3 Prevalence:

In Europe it is believed that 1 in 200 people suffer from AS (Braun 2007). Other estimates have been reported between 0.25%-1% (Calin 2004) and 0.5% (Wordsworth 2002).

Male: Female ratio has been reported from 3:1 (Snaith 2004) to 5:1 (McVeigh and Cairns 2006).

There is a clear correlation between the prevalence of HLA-B27 and AS whereby the higher the HLA-B27 prevalence, the higher the AS prevalence. There is a great variability between ethnic, racial and geographical variation (David and Lloyd 1999).

Table 1. Ethnic and racial variability in presence and expression of HLA-B27 (David and Lloyd 1999)

	HLA-B27 positive	AS and HLA-B27 positive
Western European Whites	8%	90%
African Americans	2% to 4%	48%

1.4 Signs and Symptoms: (ASAI, 2011)

- Low back pain/tenderness/stiffness with alternating buttock pain which is:
  - Worse at night or in the morning
  - Eased by activity/exercise
  - Lasted greater than 3 months
- Muscle spasm
- Fatigue
- Enthesitis (The insertion of a muscle is inflamed with possible fibrosis and calcification. Manifests as local pain and tenderness after use of the relevant muscles. e.g iliac crest, PSIS, Achilles tendon insertion.)
- Weight loss
- Mild fever
- Uveitis

Symptoms typically develop in late teens/early adulthood, but can also occur in children or later on in life (SAA 2001). Inflammatory spinal pain is commonly the first symptom of AS, which leads to reduced spinal mobility and reduced chest expansion. Initially back pain is transient, becoming constant as the condition progresses (Haroon and O Gradaigh 2009).

AS often presents differently in females who tend to have later age of onset, milder disease, more extra-axial involvement and less severe ophthalmic involvement (Snait 2004; Haroon & O Gradaigh, 2009; Lee *et al* 2007)

1.5 Clinical Features of AS

Table 2. Clinical Features of AS (Khan 2002; Wolf 2012; Van der Linden 1998)

Skeletal	Chronic low back pain and stiffness, which typically worsens following a period of prolonged inactivity (e.g., morning stiffness/stiffness after rest) Alternating buttock pain Night pain: Patients often woken up in the second half of the night with pain and often need to get up and move around before going back to sleep ↓ lumbar spine mobility in all planes especially trunk lateral flexion and rotation Abnormal posture: ↑ thoracic kyphosis and ↓ lumbar lordosis Arthritis of 'girdle joints' (hips and shoulders) Improvement of pain on exercise Muscle Spasm Enthesitis
Radiographic Features	Radiographic findings in advanced disease include erosions, sclerosis of adjacent bones, pseudo-widening of the sacroiliac joint space, and fibrosis, calcification, interosseous bridging, and ossification of the sacroiliac joints (Khan 2003).
Extraskeletal	Uveitis Fatigue Cardiovascular involvement Pulmonary involvement

Areas of Inflammation in Ankylosing Spondylitis

Eyes (40%) *common*

Jaw (15%) *rare*

Neck (75%) *common*

Shoulders (30%) *rare/common*

Ribs (20%) *rare*

Rib-Spine Junction (70%) *common*

Lumbosacral (50%) *common*

Sacroiliac (100%) *common*

Hips (30%) *rare/common*

Wrist (5%) *very rare*

Fingers (5%) *very rare*

Knee (20%) *rare*

Heel (30%) *rare/common*

Toes (5%) *very rare*
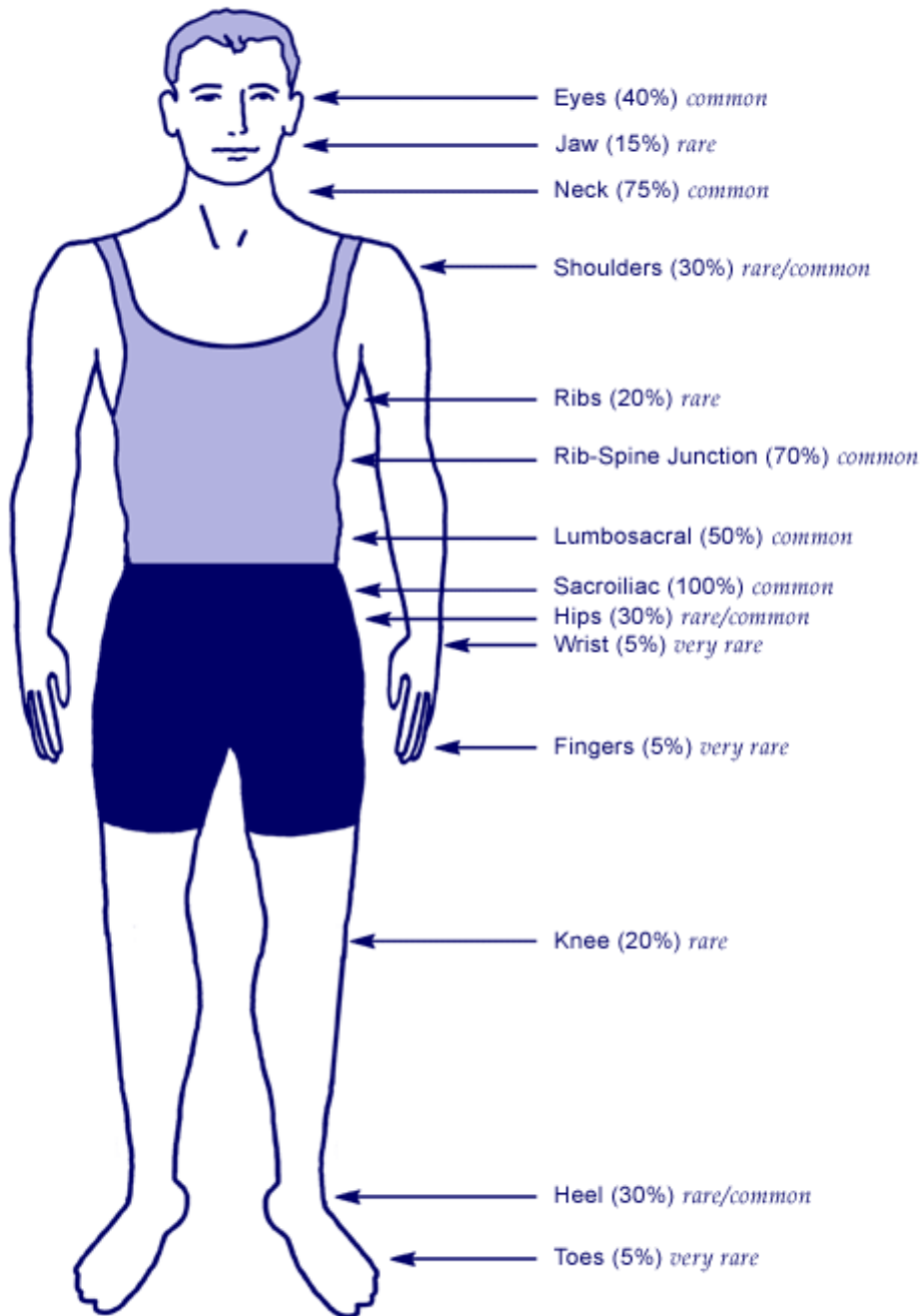
Extra Axial Joint Involvement

Hip involvement:

The hips are affected in around 30% of AS sufferers (Zochling et al 2006). It is associated with impaired functioning, which is reflected in higher overall BASFI scores compared to AS patients without hip involvement (Vander Cruyssen *et al* 2010). It has been reported that hip involvement increases the burden of the disease and its prognosis (Doran *et al* 2003).

Shoulder Involvement:

30% of AS patients are reported to have shoulder involvement. A study by Will *et al* (2000) documents that shoulder symptoms and loss of shoulder mobility is common in patients with AS and this is correlated with higher pain scores, however, it is rarely disabling.

Heel/Foot involvement:

The foot is commonly affected in AS patients (Kumar and Madewell 1987). Erdem *et al* (2005) investigated magnetic resonance imaging (MRI) of foot involvement in AS. In this study only 13% of AS patients had foot clinical signs and symptoms (pain and swelling), however the frequency of foot involvement was 91% with MRI assessment. The primary findings were bone erosions (65%), Achilles tendinitis (61%), joint effusion (43%), plantar fasciitis (40%), narrowing of joint space (40%), edema of soft tissue (30%), enthesopathy of the Achilles attachment (30%), and bony ankylosis (9%). The most common involved anatomical region was the hindfoot (83%) following by midfoot (69%) and ankle (22%).

1.6 Screening and Diagnosis of AS:

Early accurate diagnosis and intervention can minimise or even prevent years of pain and disability and modify the natural course of the disease (Salvadorini *et al* 2012). However the diagnosis of AS is often delayed as symptoms can often be confused with more common conditions such as chronic low back pain (Sieper and Braun 2011, Khan 2002). Literature indicates there is an average duration of around eight years to diagnose AS which is the longest delay of all inflammatory joint diseases (Snaith 2004).

A thorough history and medical exam, along with a physical exam to assess flexibility and joint tenderness, should be carried out by a nurse, physiotherapist or rheumatologist.

Blood tests should also be carried out which includes erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) to measure inflammatory markers in the blood. Additionally, a genetic test can determine if you have the HLA-B27 gene. >90% of people with AS in Europe carry this gene (David and Lloyd 1999).

Three sets of clinical and radiographic criteria have been introduced over the past 40 years. The Modified New York Criteria developed in 1984, are now widely used to diagnose AS (Van der Linden 1984; Van der Linden 1996).

Radiographic evidence of sacroilitis is heavily relied on to diagnose AS because it is the best nonclinical indicator of disease. Diagnosis may be missed early on, though, because routine pelvic radiographs may not clearly demonstrate sacroilitis in the initial stages of AS (Khan 2002). Often radiological changes of the sacroiliac joint become visible often after years of ongoing inflammation (Sieper and Braun 2011).

Table 3. Modified New York criteria (Van der Linden 1984)

Clinical criteria:

- Low back pain; present for more than 3 months; improved by exercise but not relieved by rest.

- Limitation of lumbar spine motion in both the sagittal and frontal planes.

- Limitation of chest expansion relative to normal values for age and sex.

Radiological criterion:

Sacroilitis on X-ray.

Diagnose:

Definite ankylosing spondylitis if the radiological criterion is present plus at least one clinical criterion.

Probable ankylosing spondylitis if three clinical criteria are present alone, *or* if the radiological criterion is present but no clinical criteria are present.

Radiographic Findings

Grading of radiographs:
The sacroiliac joints on either side should be graded separately
0   Normal
1   Suspicious changes
2   Minimal abnormality-small localized areas with erosion or sclerosis, without alteration in the joint width.
3   Unequivocal abnormality-moderate or advanced sacroilitis with one or more of: erosions, evidence of sclerosis, widening, narrowing, or partial ankylosis.
4   Severe abnormality-total ankylosis.
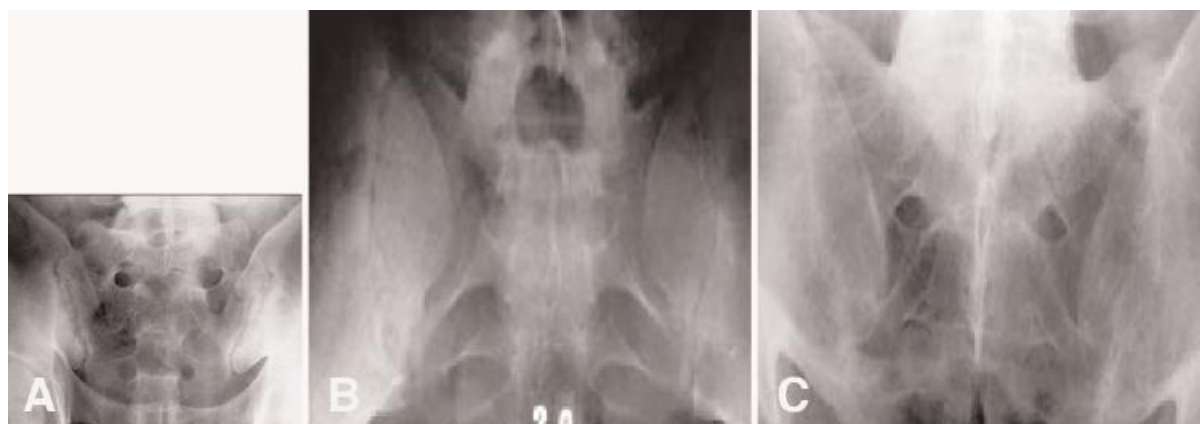
Radiographs showing examples of Grade 2 (A), Grade 3 (B), and Grade 4 (C) sacroilitis

1.7 Differential Diagnosis

Table 4. AS vs. Mechanical LBP

AS	Mechanical LBP
Early age of onset (under 45)	Older age (often over 45)
Insidious onset	Often sudden onset
Morning stiffness > 30 minutes, Stiff after sitting	Morning stiffness <15mins, Pain generally worse than stiffness
Eased with activity and worse at rest	No better/ worse on activity
Sacroiliac involvement causing alternating buttock pain	Pain tends not to alternate
Often no clear positional/ movement preference	Some movements tend to be more painful than others, frequently some directions preferred over others
75% show good or very good response to NSAIDs within 48 hours of treatment (Amor *et al* 1995)	15% of patients show good or very good response to NSAIDS within 48 hours of treatment (Amor *et al* 1995)

Distinguishing AS and disc lesion (Sharp 1997):

The main feature helping to distinguish disc lesions from AS is that in young people a disc lesion is typically as a result of a traumatic incident.

With a disc lesion- morning stiffness is not a big problem, often lasting only a few minutes and symptoms are usually worse after activity.

If as a result of a disc prolapse, there can be involvement of spinal roots with paraesthesia, selective muscle weakness and reflex changes. These are not features of uncomplicated AS.

Segmental Pain:

AS: symptoms typically not focal in distribution, but arise from wide area of the spine.

Furthermore, segmental pains are relieved by rest and aggravated by activity in contrast to AS.

Table 5. AS vs. Thoracic Spinal Stenosis

	AS	Thoracic Spinal Stenosis
Subjective	Morning stiffness Intermittent aching pain Male predominance Bilateral sacroiliac pain may refer to posterior thigh	Intermittent aching pain Pain may refer to both legs with walking
AROM	Restricted	May be normal
PROM	Restricted	May be normal
Resisted isometric movements	Normal	Normal
Special tests	None	Bicycle test of van Gelderen may be positive. Stoop test may be positive
Reflexes	Normal	May be affected in long standing cases

1.8 Prognosis:

It is estimated that 75% of AS patients with mild restriction in spinal movement who have had the disease for at least 10 years do not develop more severe spinal involvement. AS patients with severe spinal involvement will typically experience most mobility and function loss in the first 10 years of the disease (Dziedic and Hammond 2010).

Hip involvement increases the burden of the disease and worsens its prognosis (Doran *et al* 2003).

The prognosis for AS patients is excellent. The majority of patients can be treated successfully by medical and physical management of the disease. Most patients can continue to lead productive lives and do not need to change vocational plans. Morbidity associated with articular and extra-articular complications is low and lifespan is not significantly reduced, if at all (Barker et al 2007).

1.9 <u>**Comorbidities & Complications in AS patients**</u>

1. **Cardiovascular Complications**
   - Aorta Involvement
   - Conduction Abnormalities
   - Hypertension
   - Reduced Physical Activity
   - Smoking
2. **Bone Involvement**
   - Osteoporosis/Osteopenia
   - Vertebral Fractures
3. **Eye Complications**

4. **Lung Involvement**
   - Apical Fibrosis
   - Chest wall restriction & ventilatory abnormalities
5. **Cachexia**

6. **Skin Involvement**

7. **GIT Involvement**

8. **Renal Complications**

9. **Neurological Complications**

PHYSIOTHERAPY MONITORING

1. CARDIOVASCULAR COMPLICATIONS:

Cardiac pathologies are well documented complications of AS, affecting between 10 and 30% of AS sufferers (Roldan *et al* 2008). Younger patients are more at risk of cardiovasular disease (Szabo *et al* 2011). Generally, cardiac involvement in AS goes undiagnosed until the patient is symptomatic, often due to bradycardia or aortic incompetence (Kazmierczak *et al* 2008). AS patients have approximately twofold increased death rate compared to the general population, which is mainly as a result of this increased cardiovascular risk (Lautermann and Braun 2002). It is the inflammatory process that is thought to contibute to the increased cardiovascular risk. As a result it may be necessary to screen AS patients for cardiac symptoms.

Aorta Involvement:

Valvular changes in AS are described as fibrotic, thickened and retracted cusps with rolled edges. This generally leads to aortic insufficiency over time. Aortic valve disease has been reported in 4% of early AS (disease duration less than 15 years) and 10% in later stages of the disease (disease duration greater than 30 years)

Conduction Abnormalities

These are commonly observed in AS patients affecting between 3-33%. Two prevalent theories have been reported in the aetiology of conduction abnormalities in AS. Firstly there may be inflammation in the intraventricular septum leading to damage or secondly anomalies in the AV nodal artery leading to AV node dysfunction (Momeni 2001). Both processes may play a part, given that both AV blocks along with atrial and ventricular extra-systoles have been reported. A study by Dik et al (2010) found a high degree of AS patients had a first degree AV block and this was associated with duration of disease activity.

Hypertension:

The prevalence of HTN is increased in AS patients (between 8 and 18%) when compared to the general population. EULAR recommendations indicate that HTN should be managed the same as the general population. Blood pressure can be reduced through an exercise programme which can alter physiological changes associated with HTN (Peters et al 2009)

Reduced Physical Activity:

A study by Halvorsen *et al* (2012) investigated physical fitness in patients with AS. Results demonstrated lower cardiorespiratory fitness with reduced flexibility in AS patients compared to a healthy control group. Therefore physiotherapy treatment should include cardiorespiratory fitness as a component to reduce cardiovascular disease.

Smoking:

A postal survey (Mattey *et al* 2011) was carried out to determine the relationship between smoking and disease activity, pain, function, and quality of life in AS patients. 612 AS patients took part in the study. It was established that smoking had a dose-dependent relationship with disease severity measures in AS. An increase in disease activity, reduced functional ability and poor quality of life in smokers was independent of gender, age and duration of disease. Additionally AS patients that smoke have demonstrated reduced lung

volumes and exercise tolerance with reduced spinal mobility when compared to non-smokers (Kaan and Ferda 2005).

PHYSIOTHERAPY MONITORING FOR CARDIOVASCULAR COMPLICATIONS

- Avoid high intensity exercise at present
- Take into account the results of the exercise stress test, side effects of medication and the patients' current activity level.
- If starting resistance exercise for the first time with a patient then make sure they begin at a low intensity after finishing two to four weeks of an aerobic programme.
- Aerobic intensity needs to be below a level that does not induce abnormal responses but should be high enough so that there is an increase in heart rate.
  (ACSM 2010; Pollock et al 2000)

2. BONE INVOLVEMENT

Osteoporosis

Diffuse osteoporosis is a well known feature of AS. The bone loss is often present in the early stage of the disease and predominates in the spine. Studies have demonstrated that large quantities of AS patients (63%) are either osteopenic or osteoporotic affecting up to 59% and 18% of patients with AS, respectively (El Maghraoui 2004). Osteopenia and/or osteoporosis was evident in 1/3 of patients in the early stages of the disease and worsening bone loss is revealed with increasing age and longer disease duration (El Maghraoui et al 1999). Additionally, longitudinal studies have demonstrated that persistent inflammation, which is one of the major signs of AS, that is uncontrolled by medications, is a primary predictor of bone loss (Maillefert et al 2001; Gratacos et al 1999)

Overall however the cause of osteoporosis related to AS is debatable. It is postulated there are several mechanisms involved which result in bone loss including persistent inflammation, aswell as genetic factors, adverse effects to medications and a gradual reduction in spinal mobility as a result of worsening ankylosis. Additional factors such as low body weight and BMI, longer AS disease duration, reduced levels of functional ability (BASFI) and high levels of disease activity (BASDAI) and reduced activity levels are also thought to have a role in osteoporosis in AS patients (Ghozlani *et al* 2009) .

Vertebral Fractures

The reported prevalence of vertebral fractures in AS varies between 10 and 17%. A recent study investigated 80 patients with AS (average duration of disease 10.8 years) with fracture vertebral assessment using dual X-ray absorptiometry found that 18.8% of patients had a vertebral fracture. Although osteoporosis has been primarily linked to disease activity, fractures of the vertebrae appeared to be linked with duration and structural severity of the disease, as opposed to bone mineral density (Ghozlani et al 2009). Additionally, numerous studies have reported a high prevalence (up to 91%) of major neurological complications after clinical vertebral fractures (Vosse et al 2004)

Preventative treatment for bone loss and vertebral fracture is rare in AS. Often analgesia with NSAIDS and physiotherapy tend to be commonly used. Recent research has demonstrated promising results of improved bone density through the use of TNF-inhibitors (Briot et al 2008). However, it is unclear as to whether this has any impact on vertebral fractures.

PHYSIOTHERAPY MONITORING FOR BONE INVOLVEMENT:

Osteoporosis:

- There are no criteria to identify patients with AS who need bone mineral density measurements. It is up to you as a physiotherapist to be aware of the risk factors for osteoporosis and refer back to the MDT if necessary.
- Risk factors include family history, low BMI, physical inactivity, women post menopause, vitamin D deficiency (El Maghraoui, 2004).
- Additionally advice and education based on the presenting risk factors may need to be addressed in your treatment as below. Make sure your treatment does **NOT** involve any of the following:
    - Sit-ups
    - Forward flexion of spine with round back or straight legs.
    - Lifting any moderate weight
    - Rotation to point of strain (e.g. Tennis, Golf).
    - Sudden movements
    - Activities which may increase risk of falling   (Kemmis 2010)

Vertebral Fractures:

- Mostly, only AS patients with severe vertebral fractures are recognised in clinical practice as often less severe fractures can be confused with acute or chronic back pain (Ghozlani et al 2009). Therefore the physiotherapist should be aware of this when treating this pain in AS patients.

- There are a number of consequences of vertebral fractures which may be evident during patient assessment. There may be:
    - an increased spinal deformation (hyperkyphosis),
    - acute pain,
    - neurological symptoms and
    - may be associated with recent trauma or falls (Ghozlani et al 2009).

It is important therefore for the physiotherapist to assess the patient regularly for significant changes which could be indicative of a fracture.

3. EYE COMPLICATIONS

The most common eye complication is uveitis affecting 20-30% of AS patients. Additionally, uveitis prevalence increases with disease duration. It is characterised by:
- painful unilateral red eye with photophobia,
- increased tear production and
- blurred vision.

Often, it can recur but more frequently in the contralateral eye (Maghraoui 2011).

Uveitis typically resolves within 2-3 months without any residual visual impairment (El Maghraoui 2011). However, if the condition is inadequately treated it can be associated with a variety of potential complications to the eyes, including scarring of the iris to the lens, cataract formation and leakage from the blood vessels in the back of the eye. The scarring may lead to secondary glaucoma which can result in permanent loss of vision (Casell and Rose 2003)

PHYSIOTHERAPY MONITORING FOR EYE COMPLICATIONS:

Eye complications may cause the patient to have difficulty reading any material/exercises you might give them as part of their home exercise programme. Additionally they may have difficulty accurately completing an exercise as a result of blurred vision.

4. LUNG INVOLVEMENT:

Pulmonary complications have been well documented in AS patients (El Maghraoui 2005). The pathophysiology remains unclear however it is believed the most likely explanation is a disease-specific inflammatory process (El Maghraoui 2011). The lung complications include fibrosis of the upper lobes, interstitial lung disease and ventilatory impairment due to chest wall restriction, sleap apnea and spontaneous pneumothorax.

Since the development of high resolution computed tomography (HRCT) for evaluating lung involvement, it is evident that lung changes occur earlier and are more extensive than previously thought. Casserly *et al* (1997) using HRCT demonstrated lung involvement in 70% (19/26) of AS patients, in comparison to plan x-rays which revealed far less abnormalities – 15.3% (4/26) in the same patients.

Apical Fibrosis:

This is a well recognised lung abnormality in AS patients with incidence ranging from 1.3-30% and is associated with longer disease duration (Kanathur and Lee-Chiong 2010). Fibrosis can be unilateral or bilateral however the cause is unknown. It has been proposed that recurrent aspiration leading to aspiration pneumonia from defective ventilation, changes in apical mechanical stress from a rigid and stiff thoracic spine and recurrent impaired cough as a result of change in respiratory mechanics all play a role in the development of fibrosis (Thai et al 2000)

Chest Wall Restriction and Ventilatory Abnormalities:

Limited chest mobility can lead to restricted pulmonary function (Momeni et al 2011) with thoracic kyphosis leading to an impaired chest wall expansion with breathing.
A study by Maghraoui *et al* (2004) found a statistically significant correlation between PFT abnormalities and disease activity in 55 patients with AS. The major abnormality evident on PFT's is a restrictive pattern.

PHYSIOTHERAPY MONITORING FOR LUNG INVOLVEMENT:

There is limited evidence available for monitoring pulmonary function in patients with AS. It has been recommended based on expect opinion to: (El Maghraoui 2005)

- Measure chest expansion as this is positively correlated with PFT's (Sahin et al 2004).

- Check for signs of hypoventilation such as finger clubbing, cyanosis, depressed mental status and shortness of breath.

- Auscultate for ventilatory abnormalities (reduced breath sounds in apices).

- May need to refer to MDT for long-established or severe AS for PFT's and HRCT

5. CACHEXIA

This is defined as 'an accelerated loss of skeletal muscle in the context of a chronic inflammatory response (Kotler 2000). This is a catabolic process which directly results in muscle atrophy, weakness, physical disability, increased infection rate and premature death (Kotler 2000). It is believed increased levels of tumour necrosis factor (TNF) and other pro-inflammatory cytokines in the body are attributed to cachexia in AS patients.

A study by Marcora *et al* (2006) investigated muscle wasting in patients in AS. 19 patients with long standing AS (average duration 19 years) were compared to 19 age matched controls with similar levels of physical activity. Dual energy X-ray absorptiometry was used to assess body composition. Muscle strength was assessed by isokinetic knee extension, hand grip dynamometry and by 30s arm curl and chair sit-to-stand tests.

Results demonstrated that patients with AS demonstrated a clinically and statistically significant 12% reduction in arms and legs and total body skeletal muscle mass in comparison to healthy controls. This muscle loss was significantly associated with reduced upper and lower body strength. Therefore it is evident that cachexia is a functionally relevant systemic complication of AS, especially those with severe disease.
Nevertheless, body composition studies such as that above, have not consistently demonstrated a reduction in muscle mass in AS patients.

PHYSIOTHERAPY MONITORING FOR CACHEXIA:
- Physiotherapists should be aware of symptoms of cachexia such as reduced energy, weight loss, muscle wasting, and behaviours which additionally compromise energy intake, for example restlessness, malaise and anhedonia (the inability to experience pleasure from activities that are usually enjoyed. e.g. Hobbies, exercise, sexual activity or social interaction).

- Resistance training and other interventions aimed at stimulating skeletal muscle growth might be of benefit for this population.

6. SKIN INVOLVEMENT

Between 10% and 25% of AS patients are shown to have psoriasis lesions with these patients also exhibiting increased peripheral joint involvement (Maghraoui 2011). Furthermore, association with psoriasis is associated with a worse disease course in comparison to either primary AS or AS associated with inflammatory bowel disease (Lavie *et al* 2009).

PHYSIOTHERAPY CONSIDERATIONS:

- Psoriasis may be a contraindication to the use of certain therapies i.e. heat therapy, cryotherapy, Shortwave Diathermy, Laser, IF, TENS, Ultrasound if the areas affected have broken skin.
- Physiotherapists need also be aware that patients with psoriasis may not wish to wear clothing that may reveal areas affected by psoriasis and therefore may not like wearing shorts/t-shirts and other gym wear.

7. GASTROINTESTINAL TRACT (GIT) INVOLVEMENT

5-10% of patients with AS have been reported to have Crohn's disease or ulcerative colitis with subclinical gut inflammation found in 25-49% of AS patients and microscopic signs of inflammation as detected by gut biopsies found in 50–60% (De Keyser and Mielants 2003). This inflammation of the gut is closely linked to the course of the joint disease (Maghraoui 2011) with investigations showing that remission of joint inflammation is connected to a disappearance of gut inflammation (de Keyser and Mielants, 2003).

PHYSIOTHERAPY CONSIDERATIONS:

Patients with GIT involvement may be suffering from symptoms such as nausea, loss of appetite, abdominal pain and diarrhoea leading to impaired nutritional status, weight loss, fatigue and, reduced energy levels. These may all impair involvement in physiotherapy and exercise programmes.

8. RENAL COMPLICATIONS

Renal abnormalities are present in 10-35% in patients with AS. These abnormalities include glomerulonephritis, deposition of renal amyloid, microscopic haematuria, microalbuminuria

and decreased creatinine clearance and renal function (Maghraoui 2011). These abnormalities are more prevalent in aggressive and active AS and later in the disease course (Singh *et al* 2007) and can lead to renal failure.

PHYSIOTHERAPY MONITORING FOR RENAL COMPLICATIONS:
Physiotherapists need to be aware of the risk of renal complications & kidney failure in this population and the visible signs such as:
- weight loss,
- fluid retention, and
- swelling of feet, ankles and calves

which can result from kidney damage.

9. NEUROLOGICAL COMPLICATIONS

Neurological complications in patients with AS have not been thoroughly examined although they are considered to be rare, occurring more so in elderly patients with longer disease duration (Khedr *et al* 2009). The types of neurological complications noted extend from minor joint instabilities, to root lesions i.e. cervical & lumbosacral radiculopathies, to compression of the spinal cord (myelopathy) including serious clinical syndromes like cauda equina syndrome. Nerve and cord compression (related to structural changes in the axial skeleton) & inflammation are the main mechanisms causing the nervous system involvement in AS however arteritis and demyelination may also be involved (Khedr *et al* 2009).

In a study of 24 AS patients and 20 matched controls by Khedr *et al* 2009, 25% of AS patients (n=6) had abnormal neurological examinations; 8.3% presented with myelopathies and 16.7% with radiculopathies. Although, this is a small scale study using now outdated imaging methods results, it does highlight the frequency of subclinical neurological complications in patients with AS compared to clinically manifest complications.

PHYSIOTHERAPY MONITORING FOR NEUROLOGICAL COMPLICATIONS:
Physiotherapists must monitor AS patients for signs of neurological compromise in particular screening for signs of serious spinal cord compression and cauda equina syndrome e.g. urinary retention, increased frequency of urination, loss of bowel control, numbness/loss of sensation in the saddle area, gait disturbance.

1.10   Outcome Measures for Assessment of AS

BASFI- Bath AS Functional Index

The BASFI is a set of 10 questions designed to determine the degree of **functional limitation** in those with AS. It is measured using a visual analogue scale (ranging from 0 being easy and 10 being impossible) and the questions are focused on the person's ability to perform specific functional tasks. The first 8 questions consider activities related to functional anatomy, such as putting on socks with or without help and climbing steps with or without using a handrail. The final two questions assess the patients' ability to cope with everyday life. It is included in the ASAS core sets for AS assessment. The BASFI has shown to have high levels of validity and reliability when measuring functional ability in AS (Ruof and Stucki 1999).

*(Calin *et al* 1994)*

Dougados Functional Index

Index to assess the functional abilities of people with AS. The index includes 20 questions asking patients to report their ability to complete activities of daily living. Questions are answered with a 3-point scale.

- 0= yes, with no difficulty
- 1=yes, but with difficulty
- 2=impossible

Item scores are then added to give a total score of dysfunction. The total score ranges 0-40.

The DFI was one of the first-generation functional indices created to evaluate the ability of persons with AS. However, despite having a high degree of validity and reliability, the narrow range of scores makes the index insensitive to changes in functional ability.

(Rouff and Stuck 1999)

Comparing BASFI and the Dougadas

Using a sample of 47 AS inpatients and 116 AS outpatients, a study by Calin et al (1994) compared the BASFI and The Dougados Functional Index. Results showed:

1. BASFI and Dougados took an equivalent amount of time to complete: 100 seconds max
2. Subjects expressed no preference for either instrument.

3. The BASFI scores illustrated a better distribution – 0 to 9.5 compared with 0 to 6.5 for The Dougados.

4. The reproducibility of both scores was statistically significant (p<0.001).

5. Inter-observer reliability was statistically significant (p<0.001) for both scores.

6. Over a 3 week treatment period:

- The BASFI scores demonstrated a significant (p=0.004) 19.6% improvement
- However the 5.9% improvement in the Dougados scores was insignificant.

✓ Results 3 and 6 demonstrate the benefits of The BASFI over the Dougados Index. The VAS used in The BASFI gives a broader range of answers to the 3 scale response of the Dougados where the middle option (yes, but with difficulty) is very vague and does not distinguish between minor and major difficulty. The VAS in The BASFI thus gives a greater representation of the population and it would also explain the greater degree of sensitivity shown by the BASFI.

(Calin et al 1994)

BASDAI: Bath AS Disease activity Index

The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) is the gold standard for measuring and following **disease activity** in Ankylosing Spondylitis *(*Garrett *et al* 1994).

Like the BASFI, the BASDAI consists of 10cm visual analogue scales used to answer 6 questions pertaining to the 5 major symptoms of AS:

- Fatigue
- Spinal pain
- Joint pain/swelling
- Areas of localized tenderness
- Morning stiffness
  ✓ Intensity
  ✓ Duration
  ✓ The questions are answered on a 10 cm VAS, anchored with the labels "none" and "very severe" at either end of the first five questions, and with "0 hours" and "two hours" at either end of the question on duration of morning stiffness. The mean of the

two scores for morning stiffness counts as one variable. The final score is defined by calculating the mean of the five items. Final scores range from 0 (best) to 10 (worst).

✓ A BASDAI score >4 is internationally accepted to indicate active disease, and most clinical trials of therapy in AS now require that patients have active disease as defined by a BASDAI score of >4 for inclusion.

When clinically tested, results showed:

1. BASDAI to be a quick and simple index, taking between 30 seconds and 2 minutes to complete.
2. BASDAI demonstrated statistically significant ($p<0.001$) reliability.
3. The individual symptoms and the index as a whole demonstrated good score distribution, using 95% of the scale.
4. Following a 3 week physiotherapy course, the BASDAI showed a significant ($p=0.009$) 16.4% score improvement, therefore demonstrating a sensitivity to change.

(Garrett et al 1994)

To conclude, the BASDAI is user friendly, highly reliable, reflects the entire spectrum of the disease, and is sensitive to clinical changes.

BASMI- Bath AS Metrology Index

To accurately assess **axial status** (cervical, dorsal and lumbar spine, hips and pelvic soft tissue) of individuals with AS and from these derive a metrology index to define clinically significant changes in **spinal mobility.** (Jenkinson *et al*, 1994)

Five clinical measurements were included in the index:

1. Cervical rotation (degrees of motion)
2. Tragus to wall distance (centimetre tape measure)
3. Lumbar side flexion (centimetre tape measure)
4. Modified Schober Test centimetre tape measure)
5. Intermalleolar distance (centimetre tape measure)

A BASMI score from between 0 to 10 is calculated after the clinical exam is performed and each of the 5 measurements is obtained. The range of severity 0-10 reflects mild to moderate disease activity and functional ability in the spinal column. The higher the BASMI score the more severe the patient's limitation of movement due to their AS. *(Jones et al,1995)*

BAS-G: Bath AS Patient Global score

The impact of AS from the patients' perspective encompasses all aspects of disease including activity, function and structural damage, in one summary measure. The patient global assessment is useful in clinical practice, and may be the single most responsive measure in this setting.

The Bath Ankylosing Spondylitis Global score (BAS-G) is consistent with the other measures in the core set, utilizing the 'in the last week' approach to obtain a snapshot of current patient status but also it also refers to the patient's average well-being over the last 6 months, which can be helpful to describe longer-term disease progression.

The BAS-G consists of two questions which ask patients' to indicate, on a 10cm VAS, the effect the disease has had on their well-being over the

- last week
- last six months.

The mean of the two scores gives a BAS-G score of 0 – 10. The higher the score, the greater the perceived effect of the disease on the patient's well-being.

In a study of the BASGI involving 177 AS inpatients and 215 patients reached by a postal survey, the author found that:

- BAS-G scores covered the whole 0 – 10 scale for both time frames (1 week & 6 months).
- BAS-G correlated well with both BASDAI and BASFI. This suggests that disease activity and functional ability play a major role in patients' well-being – more than metrology.
- Of the 5 BASDAI items, spinal pain followed by fatigue correlated best with BAS-G. This highlights the importance of pain and fatigue to the patient.
- BAS-G demonstrated statistically significant ($p<0.001$) sensitivity to change. (Jones et al 1996)

Visual Analogue Scale

Pain-VAS and stiffness-VAS are VAS (10cm line) for pain and stiffness respectively. The total score range is 0-10. The VAS allows a broader range of possible answers with greater ease, and therefore gives a better representation of the assessed population. Also, this scale allows for smaller changes to be identified (Zochling *et al* 2005)

ASQoL (AS Quality of Life)

The measurement of health-related quality of life is not included in the ASAS core sets, but is worthy of consideration as a component of patient assessment, as it incorporates all three facets of disease – activity, function, and damage. There are now validated AS-specific instruments to measure disease-related quality of life.

The most thoroughly studied is the Ankylosing Spondylitis Quality of Life (ASQoL) questionnaire, an 18-item scale with dichotomous responses (yes/no) relating to the impact of the disease on sleep, mood, motivation, coping abilities, activities of daily living, social life, relationships and independence (Doward *et al* 2003).

Doward et al (2003) stated that the ASQoL will allow accurate assessment of the effectiveness of interventions from the patient's perspective. However, future research needs to be done to determine the ability of the instrument to detect meaningful changes in QoL.

The ASQoL is easy to administer and correlates well with the well established generic EuroQol Doward et al (2003), but has been criticized for omitting important patient factors such as body image and walking. It has been shown to be responsive in clinical trials of anti-TNF-alpha therapy, but less useful to measure changes after physiotherapy or standard care.

Arthritis Impact Measurement Scale 2 (AIMS 2)

Disease-specific measure of physical, social, and emotional well-being designed as a measure of outcome in arthritis. Consists of 63 items using a 5 point scale for each response (Guillemin *et al* 1999).

AIMS2 has good psychometric properties. The full-length versions are quite time consuming to complete, and the short-form (AIMS2-SF) that has similar psychometric properties to the full-length versions, may be more appropriate for postal surveys, studies where patients are required to complete several questionnaires, and in clinical practice.   *(*Ren *et al* 1999*)*

Table 6. Assessment of SpondyloArthritis international Society (ASAS) core set for symptom modifying anti-rheumatic drugs (SM-ARD) and physical therapy.

Domain	Instrument
Function	BASFI
Pain	NRS/VAS (Last week/spine/at night due to AS)
	NRS/VAS last week/spine/due to AS
Spinal Mobility	BASMI
	Chest Expansion
	Modified Schober
	Occipital to wall
	Cervical Rotation
	Lateral Spinal flexion
Patient Global	NRS/VAS (Global disease activity last week)
Stiffness	NRS/VAS (duration of morning stiffness/spine/last week)
Fatigue	Fatigue Question BASDAI

Table 7. Extra domains of ASAS core set for clinical record keeping and disease-controlling anti rheumatic diseases (DC-ART)

Domain	Instrument
Peripheral Joints and entheses	Number of swollen joints (44 - joint count)
X Ray Spine	Lateral lumbar spine and lateral cervical spine
Acute phase reactants	C – reactive protein (CRP) or erythrocyte sedimentation rate (ESR)

1.11 Imaging

The ASAS core sets recommend plain x-ray of the pelvis to view the sacroiliac joints, because this includes both the sacroiliac joints and the hips, is not inferior to specific sacroiliac views, and minimizes exposure to irradiation.

There are currently two main validated scoring systems used to assess spinal structural damage in clinical trials in AS: a modified SASSS (mSASSS) and the Bath Ankylosing Spondylitis Radiographic Index (BASRI).

- BASRI is an X-ray scoring system for the lateral cervical spine, AP and lateral lumbar spine and hips, using the modified New York system to grade the sacroiliac joints.
- The mSASSS is also an X-ray scoring system for the lateral cervical and lateral lumbar spine, with the score ranging from 0-72.

- The BASRI is not sensitive to change over periods of 1 to 2 years, possibly due to the relatively slow progression of disease in many patients with AS. The Modified stokes Ankylosing Spondylitis spinal scale (mSASSS) performs better, having been shown to detect changes over 24 months in population studies (Wanders et al 2004).

Table 8. Summary of Outcome Measures used in the assessment of AS

Scale	Domain	Response	Method	Duration	Scale	Evidence
BASFI	Functional Capacity	VAS 0-10	Patient self-report	100 sec max	0(easy) – 10 (impossible)	Valid Reliable Sensitive to change (Calin *et al* 1994)
BASDAI	Disease Activity	VAS 0-10	Patient self-report	30sec-2mins	0(easy) - 10 (impossible)	Quick and simple index Valid Reliable Sensitive to change (Garrett *et al* 1994)
BASMI	Spinal Mobility	Clinical Ax	Clinical Ax	7 mins	0(mild disease involvement) -10(severe disease involvement)	Valid Reliable Sensitive to change Scoring system has been further enhanced to improve the instruments usefulness (Jones *et al* 1995)
BAS-G	Global well-being	VAS 0-10	Patient self-report	1 min	0(no effect)-10(very severe effect)	Valid Sensitive to change BAS-G correlated well with both BASDAI and BASFI. Of the 5 BASDAI items, spinal pain followed by fatigue correlated best with BAS-G. This highlights the importance of pain and fatigue to the patient. (Jones *et al* 1996).
DFI	Functional Capacity	0-2 scale	Patient self-report	2 min	0= yes, with no difficulty 1=yes, but with difficulty 2=impossible to do	Despite having a high degree of validity and reliability, the narrow range of scores makes the index insensitive to changes in functional ability (Rouf *et al* 1999)
ASQoL	QoL	Yes/No	Patient self-report	<4 min	Yes=QoL adversely impacted No=QoL not impacted	Reliable Valid Has been criticized for omitting important factors such as body image and walking (Haywood, 2005)
AS-AIMS 2	QoL	0-5 scale	Patient self-report	15-20 mins	Different scale for each subscale ranging from 0-5	Reliable and valid Time consuming (Guillemin *et al* 1999)

1.12 Laboratory Investigations

Acute Phase Reactants

Laboratory investigations in AS should include the erythrocyte sedimentation rate (ESR) or C-reactive protein (CRP) as a measure of inflammation (an indicator of disease activity). Although neither measure is diagnostic for AS, acute phase reactants are likely to be raised in patients who have peripheral joint involvement. Neither measure is superior for disease assessment in AS (Ruof and Stucki 1999). However the ESR has been chosen as the preferred reactant by the ASAS core sets for reasons of cost and availability.

Assessing Treatment Response

The assessment of disease response to therapy using the ASAS Response Criteria is a valuable means of determining treatment efficacy and allows comparison of response across trials and interventions. The ASAS group has taken the core sets and their respective measurement instruments to construct specific composite response criteria for use in measuring the treatment response in AS trials (Table X). Derived from 5 short-term trials of NSAIDs in AS, the initial improvement criteria consist of four outcome domains: physical function, spinal pain, patient global assessment and inflammation (Anderson et al 2001).

Improvement is defined as a 20% improvement from baseline, or a 10 mm improvement from baseline for VAS measures on a 0-100 mm scale, in at least 3 of the 4 domains. There cannot be deterioration of 20% or more, or of 10 mm or more on a VAS scale, in the corresponding 4th domain.

The response criteria show high specificity and moderate sensitivity and have been validated in studies of anti-TNF alpha therapy (Stone et al 2004). These are now termed the ASAS 20% response criteria (ASAS20), and allow the calculation of treatment response as a dichotomous variable, 'responder' and 'nonresponder', and subsequent calculation of the number needed to treat (NNT) for interventions in AS.

Further investigation of the response criteria has introduced variations in the ASAS-IC which appear to perform better in defining the treatment response, specifically in anti-TNF-alpha studies. Further validation of these new modifications to the response criteria is ongoing.

Table 9. ASAS Response Criteria

Instrument	Abbreviation	Description
ASAS improvement criteria	ASAS-IC	Four domains, based on the discrimination between NSAID treatment and placebo - Physical function, measured by the BASFI - Spinal pain, measured on a 0-100mm VAS - Patient global assessment in the last week, on a 0-100mm VAS - Inflammation, measured as the mean of the last 2 BASDAI questions (intensity and duration of morning stiffness)
ASAS 20% response criteria	ASAS20	Treatment response is defined as: - $\square\square$20% and $\square$10mm VAS on a 0-100 scale in at least 3 of the 4 ASAS-IC domains, and - No worsening of $\square\square$20% and $\square\square$10mm VAS on a 0-100 scale in the remaining 4th domain
ASAS 40% response criteria	ASAS40	Treatment response is defined as: - $\square$40% and $\square$20mm VAS on a 0-100 scale in at least 3 of the 4 ASAS-IC domains, and - No worsening of $\square$40% and $\square$20mm VAS on a 0-100 scale in the remaining 4th domain
ASAS 5/6 response criteria	ASAS5/6	Developed for use in trials of anti-TNF therapy, six domains were included: - Pain - Patient global assessment - Function - Inflammation - Spinal mobility - C reactive protein (acute phase reactant) Treatment response is defined as improvement in 5 of 6 domains without deterioration in the 6th domain, using predefined % improvements.

Section 2. Management

2.1 Medical Management of AS

Medical Management of AS				
NSAIDs	Analgesics	Steroids	TNF - α Inhibitors	DMARDs
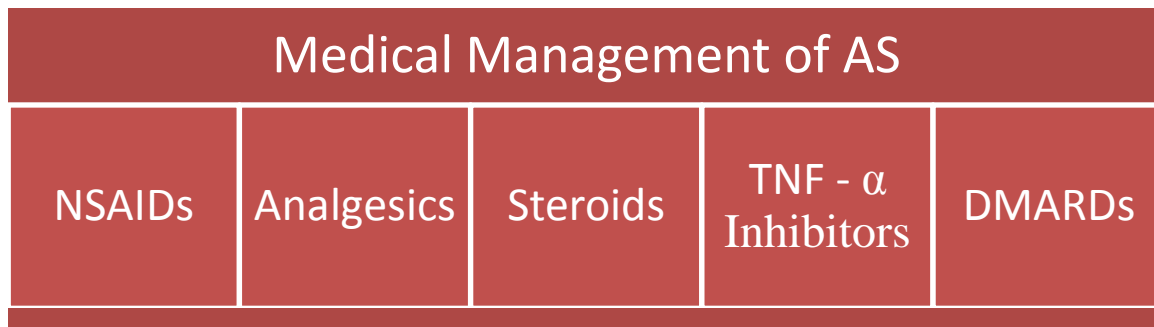
Non-Steroidal Anti-Inflammatory Drugs (NSAIDs)

➡ Traditional NSAIDs: Ibuprofen

Diclofenac

Naproxen

Indomethacin

➡ COX-2 Inhibitors: Celecoxib

Etoricoxib

Mechanism of Action

NSAIDs block the COX enzymes and reduce prostaglandins throughout the body i.e. they reduce the synthesis of inflammatory mediators.

Diagram 1. Mechanism of Action of NSAIDs
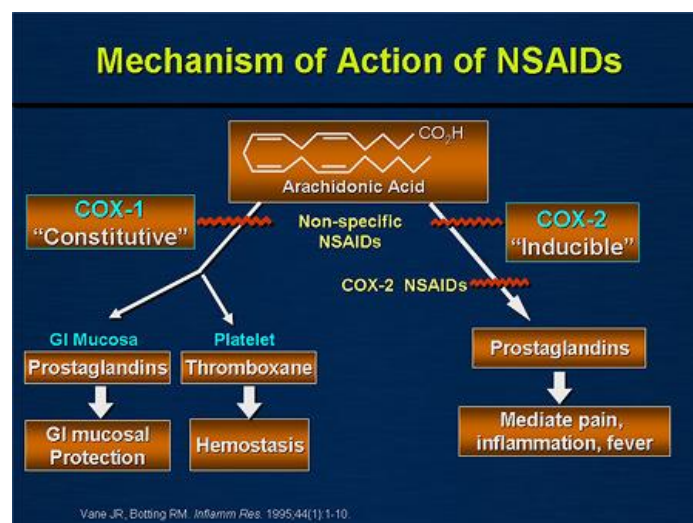
Uses of NSAIDs in AS

- Improvements in spinal and peripheral joint pain

- Improvement in function (over a short period of time – 6 weeks)

- Improvement in enthesitis   (Zochling et al 2006)

Side-effects of NSAIDs

- Increased risk of GI bleeding and perforation

- Nausea

- Vomiting

- Diarrhoea

- Constipation

- Decreased appetite

- Rash

- Dizziness

- Drowsiness

- Fluid retention leading to oedema

- Serious but rare side-effects:

    o Kidney failure

    o Liver failure

    o Ulcers

    o Prolonged bleeding following injury or surgery

<u>Recommendations for NSAIDs in AS management</u>

- First line drug treatment for AS patients with pain and stiffness

- Continuous treatment with NSAIDs is preferred for patients with persistently active and symptomatic disease.

- Cardiovascular, GI and renal risks should be considered prior to commencement of NSAIDs.   (Braun et al 2010)

<u>Other comments</u>

- There is no clear evidence that NSAIDs alter the structural progression of the disease. This, and the side-effect profile of these drugs, has led clinicians to use NSAIDs for

symptomatic control rather than as continuous therapy in the majority of patients. (NICE 2008)

- The inhibition of COX-1 is what results in irritation of the stomach lining. This is due to the fact that COX -1 is cyto-protective when produced by the gastric mucosa (Vane *et al* 1998). To prevent GI irritation, the use of a selective COX 2 inhibitor is employed. If non-specific NSAIDs are being used, the complementary use of a gastro-protective agent should also be utilised. (Zochling *et al* 2006)

- About 75% of AS patients show good or very good responses to NSAIDs within 48 hours of commencement, compared with only 15% of patients with mechanical low back pain ➡ Differential Diagnosis. (Kain *et al* 2008)

Analgesics

➡ Paracetamol

➡ Opioids

Uses: To control pain

Mechanism of Action

- Paracetamol: It is a weak inhibitor of prostaglandin synthesis. There is considerable evidence that the analgesic effect of paracetamol is central and is due to activation of descending serotonergic pathways, but its primary mode of action may still be inhibition of PG synthesis. (Garry *et al* 2005)

- Opioids: inhibition of the release of glutamate from peripheral nociceptors and postsynaptic neurons in the dorsal horn. They reduce the intensity of pain signals reaching the brain and affect those brain areas controlling emotion, which diminishes the effects of a painful stimulus.

*Prostaglandins are lipid autacoids derived from arachidonic acid. They both sustain homeostatic functions and mediate pathogenic mechanisms, including the inflammatory response. They are generated from arachidonate by the action of cyclooxygenase isoenzymes, and their biosynthesis is blocked by nonsteroidal antiinflammatory drugs

*Glutamate is an amino acid precursor. It is the most common excitatory neurotransmitter in the central nervous system (CNS). (National Institutes of Health 2012)

Table 10. Side-Effects of Analgesics (Benyamin *et al* 2008)

Common Side-Effects	*Rare Side-Effects*
Sedation	Delayed gastric emptying
Dizziness	Hyperalgesia
Nausea	Muscle rigidity
Vomiting	Myoclonus
Constipation	
Physical dependence	
Tolerance	
Respiratory depression	

Recommendations for AS management

- Considered for residual treatment following the failure of previously recommended treatments, contraindication to other treatment methods or poor tolerance to other treatment options.

(Zochling *et al* 2006)

Other comments

- May be used as an adjunct treatment to NSAIDs.

Corticosteroids

➡️Prednisolone

➡️ Cortisone

➡️Corticosteroid Injection

Mechanism of Action

Corticosteroids combine with steroid receptors in the cytoplasm of cells; this combination then enters the nucleus. The formation of a protein which is inhibitory to the enzyme phospholipase A2 occurs. This enzyme is needed for the supply of arachidonic acid which is responsible for the production of inflammatory mediators. Therefore, corticosteroids reduce inflammation from inhibiting the synthesis of inflammatory mediators.

*Arachidonic acid is a polyunsaturated fatty acid which is present in phospholipids of membranes of the body's cells especially the brain, muscle and liver cells. It is oxygenated and transformed into a variety of products which mediate inflammatory reactions (National Centre for Biotechnology Information 2012).

<u>**Uses**</u>

Targeting local inflammation:

- Axial joints – SIJ, costovertebral and manubriosternal joints.
- Peripheral joints – asymmetric oligoarthritis with predominance in the lower limbs
- Enthesitis – plantar fasciitis, Achilles enthesitis and patellar tendon insertion enthesitis.

<u>**Side-Effects**</u>

- Elevated pressure in the eyes (Glaucoma)
- Cataracts
- Fluid retention leading to oedema
- Increased blood pressure
- Altered blood sugar levels which can trigger or worsen diabetes
- Mood swings
- Weight gain
- Increased risk of tendon rupture
- Increased risk of osteoporosis and subsequent fracture
- Increased risk of infection
- Suppressed adrenal gland hormone production
- Delayed wound healing
- Acne
- Pain, infection, shrinking of soft tissue and loss of colour at injection site.

Recommendations for AS management

- Glucocorticoid (also known as corticosteroid) injections directed to the local site of musculoskeletal inflammation may be considered.
- Intra- or peri-articular glucocorticoid injections have been shown to be effective for the pain of sacroilitis in small RCTs (level 1b evidence)
- The use of systemic glucocorticoids for axial disease is not supported by the evidence.

TNF – α Inhibitors

What is TNF- α?

TNF-α plays an important role in the pathology of AS. It is a pro-inflammatory cytokine leading to subsequent pain, tenderness, swelling and fever (Zochling et al 2009). It is predominantly produced by macrophages and monocytes but it is also produced by B-cells, T-cells and fibroblasts. Increased amounts of TNF-α have been found in the serum, synovium and sacroiliac joints (site of inflammation) of patients with AS (Zou *et al* 2002).

*A cytokine is any of numerous regulatory proteins including the interleukins and lymphokines. They are released by immune system cells and function as intercellular mediators in generating an immune response (Genetics Home Reference 2013).

TNF-α stimulates the expression of adhesion molecules by endothelial cells. It also stimulates synovial cells to produce collageneses. It recruits WBCs in the inflamed synovium and skin. It stimulates fibroblast proliferation. TNF-α is responsible for the induction of the production of other inflammatory cytokines (e.g. IL-6) and for the induction of bone and cartilage resorption.

TNF – α Inhibitors

➡ Adalimumab (subcutaneous injection)

➡ Infliximab (intravenous)

➡ Etanercept (subcutaneous injection)

Mechanism of Action

- Adalimumab is a recombinant human-sequence monoclonal antibody specific to TNF-α (Zochling *et al* 2009). It binds specifically to TNF-α and neutralises its biological function by blocking its interaction with cell-surface TNF-α receptors.
- Infliximab is a chimeric monoclonal antibody that binds to TNF-α with a high affinity to neutralise its activity
- Etanercept is a receptor fusion protein that binds to TNF-α. By doing this it inhibits the binding of TNF-α to the cell surface (Zochling *et al* 2009).

(NICE 2008)

Uses
- Spinal pain
- Function
- Peripheral joint disease

Side-Effects

- Fever
- Headache
- Cough
- Diarrhoea
- Musculoskeletal pain
- Injection site reactions
- Allergic reactions
- CNS demyelinating disorders
- Heart Failure
- Acute infusion-related reactions
- Increased frequency of infections e.g. TB
- Delayed hypersensitivity reactions
- Increased frequency of cancer (rare)

Recommendations for Anti-TNF-α AS management

- According to the ASAS recommendations, anti-TNF therapy should be given to patients with persistently high disease activity despite conventional treatments.

- The use of essential Disease Modifying Anti-Rheumatic Drugs (DMARD) therapy before or simultaneously with anti-TNF therapy for patients with axial disease is not supported by the evidence.

- There is no evidence to support a variance in efficacy of the different TNF inhibitors on the axial and entheseal aspects of the disease. However, if inflammatory bowel disease is present this will need to be taken into account.

- TNF inhibitors are the only biologic agents with evidence for effect in AS.

- If there is a lack of response to one TNF inhibitor, it may be beneficial to trial another one.

Cochrane 2009: TNF-α inhibitors for AS

- Biologics are effective in AS (Brandt 2000, Makysmowych 2002, Marzo-Ortego 2001, Stone 2001, Haibel 2004)

- They are highly effective in improving disease activity, spinal mobility, function and pain (Braun 2002; Van Den Bosch 2002; Gorman 2002)

NICE Guidelines 2008: Adalimumab, etanercept and infliximab for Ankylosing Spondylitis

The following criteria must be met:

- Diagnosis of AS according to the New York Criteria

- Confirmed sustained active spinal disease:
  - A score of at least 4 units on the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) &
  - At least 4cm on a 0-10cm VAS for spinal pain
    - These two criteria should be demonstrated on two separate occasions at least 12 weeks apart without any change in treatment methods.

- Failed symptomatic control via conventional therapy using two or more NSAIDs taken sequentially at maximum tolerated/recommended dosage for at least four weeks.

Disease Modifying Anti-Rheumatic Drugs (DMARDs)

➡ Methotrexate
➡ Sulfasalazine
➡ Gold (Injection)
➡ Azathioprine
➡ Ciscoporin
➡ Leflunomide

Mechanism of Action

The mechanism of action of DMARDs is not yet clearly understood. It is believed that they slow down the disease process through alteration of the immune system.

Uses

- Treatment of peripheral joint disease
- No evidence of effect for spinal association especially in patients with longer-standing disease.

Side-Effects
- Gastric irritation
- Pericarditis
- Hypotension
- Skin rashes
- Mouth sores
- Myelosuppression
- Headaches
- Dizziness
- Fatigue
- Bone marrow suspension (lowers bone marrow count)
- Pulmonary oedema

Recommendations for management of AS

- Sulfasalazine may be considered for the treatment of peripheral arthritis, especially in those patients with newer diagnosed AS.
- There is no evidence for the use of DMARDs in the treatment of axial disease in AS.

Other Comments

There is "gold" level evidence that sulfasalazine has a positive effect on morning stiffness and ESR in people with AS.

However, the evidence regarding sulfasalazine and its effect on pain, function and spinal mobility is inconclusive. (Chen and Liu 2009)

2.2 Surgical Management

Surgical Management		
Total Hip Arthroplasty (THA)	Spinal Corrective Surgery	Surgical Correction of TMJ Ankylosis

Total Hip Arthroplasty (THA)

Recommendations

THA should be considered in patients with refractory pain or disability and radiographic evidence of structural damage, independent of age. (Braun *et al* 2010)

THA is an excellent intervention for AS patients who suffer from advanced symptomatic hip involvement. (Braun et al 2005)

<u>Outcomes</u>

- Improved pain and function   (Bhan et al 2008)
- 96% of patients had excellent pain relief and 65% had excellent hip function post THA. 71% prosthesis survival rate after 27 years.   (Joshi *et al* 2002)
- Significant improvements in pain, function and range of motion. (Brinker et al 1996)

<u>Indications</u>
- Refractory pain
- Disability
- Radiographical evidence of structural damage
- Stiffness
- Fixed flexion deformity
- Precursor to corrective osteotomy of the spine

<u>General Physiotherapy management post-THA</u>
- Home Exercise Programme (HEP) incorporating:
    - Range of Motion
    - Strength
    - Postural Stability
    - Functional Exercises
- Outpatient physiotherapy:
    - Aerobic dance routines
    - Individual treatment sessions
    - Exercise classes
    - Supervised strengthening sessions
- Combined HEP and outpatient approach
- Precautions post-THA

Evidence of effectiveness is largely inconclusive (Minns-Lowe *et al* 2009)

Spinal Corrective Surgery

Background

- AS leads to chronic pain, deformity and fracture of the axial skeleton.
- The disease process alters the biomechanics of the spine through a chronic inflammatory process resulting in a brittle minimally compliant spinal column.
    - Inflammation (in the vertebral body) leads to erosions where the annulus fibrosis of the intervertebral disc inserts. This results in squared vertebrae with "shiny corners" (Romanov lesions).
    - Synovitis also occurs at the facet joints
- This means that AS patients are highly susceptible to unstable spinal fractures and neurological impairment with minimal trauma.

(Westerveld *et al* 2009)

Spinal Fractures

- Four times more likely in AS population than the general population.
- Related spinal cord injury in two-thirds of presentations associated with traumatic injury (Westerveld *et al* 2009)
- AS patients are also at increased risk of falling due to:
    - Altered gait
    - Impaired balance
    - Compromised horizontal gaze due to fixed spinal deformity
    - Advanced age
    - Longer disease duration
    - Alcohol abuse
    - Progressive kyphosis

Falls then also lead to increased risk for spinal fractures.

Cervical Fractures

- The subaxial cervical spine is the most frequent area for spinal fractures in AS
- Very unstable and increased risk of neurological deficit (29-91%) and double the mortality rate (35%) of the normal population.
- Patients have difficulty distinguishing pain from acute fracture to that of their chronic inflammatory pain.

Thoracolumbar Fractures

- Less common than cervical. Many occur at the thoracolumbar junction.
- Three types:
    - Shearing injury
    - Wedge compression
    - Pseudoarthrosis from chronic malunion

Consensus regarding optimal treatment of spinal fractures for AS patients is inconclusive. Conservative management by means of immobilisation may be sufficient however many patients cannot tolerate this method.

Surgery should be carried out when there is a presence of spinal instability and acute or worsening neurological symptom

(Westerveld *et al* 2009, Chaudhry *et al* 2011)

Indications for surgical management

- Deteriorating neurological status
- Irreducible deformity
- Epidural haematoma
- Other source of spinal cord compression
- Cauda Equina Syndrome
- Progressive myelopathy

Surgical management

Indicated for 1 in 200 patients (Braun et al 2005)

- Antero-posterior approach: increased risk of mortality and morbidity, frequent pulmonary co-morbidities of AS pts.
- Single posterior approach
- Staged procedures:
    - Medically tenuous patients
    - Minimally invasive fixation techniques using percutaneous screw fixation should be considered for initial and immediate stability across an unstable fracture, followed by a formal open fusion procedure.

(Chaudhary *et al* 2011)

Types of Surgery

- **Decompressive laminectomy**: spinal cord compression or worsening neurological status. Sound bony fixation and stability along with a good fusion bed.
- **Opening-wedge osteotomy**: correction of kyphotic deformity in the lumbar spine.
  - No sufficient evidence based evaluation of this method.
- **Polysegmental wedge osteotomy with internal fixation**: post-operative satisfaction rates are poor:
  - Successful in 47-80% of cases
  - Fair in 16-67% of cases
  - Poor in 5-14% of cases   (Hehne *et al* 1990, Van Royen *et al* 1998)
- **Monosegmental intravertebral closing-wedge posterior osteotomy of the lumbar spine:** correction of lumbar lordosis. Mixed evidence regarding this technique (Royen et al 1995, Lazennac et al 1997)
- **Combined approach** allowing simultaneous access to the anterior and posterior spine in one surgical session – excellent correction of disturbed sagittal profile and with restoration of a horizontal axis has been achieved in all patients in a study by *El Saghir et al 2002*.
- **Surgical fusion:** progressive atlantoaxial subluxation.
  - Bone graft options for fusion:
    - Local bone from decompression
    - Rib harvest – increased risk of pulmonary complications
    - Iliac crest bone graft – **GOLD STANDARD** – but may limit patients post-operative mobilisation which could lead to pulmonary complications.

Evidence Base

Surgical outcome after spinal fractures in patients with ankylosing spondylitis (Sapkas *et al* 2011)

- 20 AS patients receiving surgery for spinal fracture (7 cervical, 9 thoracic, 3 thoracolumbar junction, 1 lumbar)
- Combined ant & pos approaches in three patients. Posterior alone in the remaining.

- No intra-operative complications

- Frankel neurological classification was used to evaluate the neurological status of the patients.

- Surgery improved patient's neurological status (where it was affected) as per Frankel classification.

  o Wilcoxin Signed Ranks Test: statistical significant improvement of the Frankel classification from the pre-operative to the post-operative phase (p = .015).

- The operative treatment is useful and successful.

*__Frankel Neurological Classification__ is a grading system of acute spinal cord injury:

- **Grade A**: Complete neurological injury – no motor or sensory innervation detected below the level of the injury.

- **Grade B:** Preserved sensation only – no detection of motor function clinically, below the level of the injury. Sensory function remains below the level of the injury but may only include partial function.

- **Grade C:** Preserved motor function but it is non-functional.

- **Grade D:** Preserved useful motor function below the level of the injury. The patient can move the lower limbs and walk aided or non-aided but will have an impaired gait pattern.

- **Grade E:** Normal motor, no clinically detected motor or sensory function abnormalities. Normal sphincter function will be present. Abnormal reflexes and subjective sensory abnormalities may be present.

(Narenthiran 2007)

General Physiotherapy management following spinal surgery

There are inconsistencies regarding post-surgery protocols. Evidence of continuing and significant uncertainty as to what does constitute best care in this area of practice. Conducting further large, rigorous, randomised controlled trials would be the best method for obtaining definitive answers to these questions.

Temporomandibular Joint (TMJ) Ankylosis
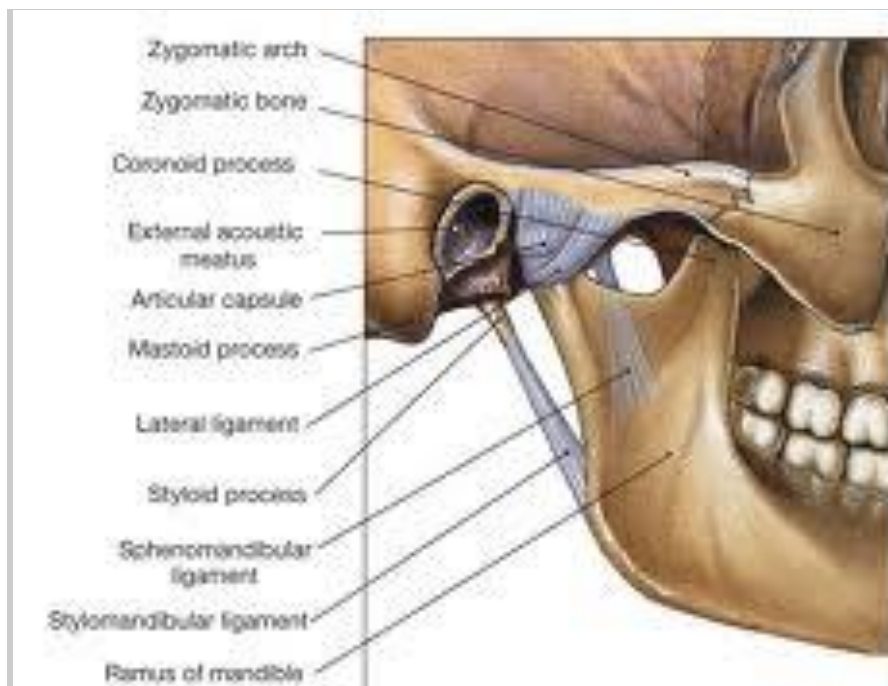
Background

- The TMJ is formed by the mandibular condyle and the glenoid fossa of the squamous part of the temporal bone.
- It has upper and lower cavities which are separated by a fibrocartliagenous disc.
- It is a diarthoidal atypical synovial joint.
- Rotational and translator movements are available at the TMJ
- TMJ involvement is not uncommon – tends to present in older patients with extensive spinal and peripheral disease.

(Felstead *et al* 2011)

Ankylosis of the TMJ

- Very disabling affliction however only 11 cases worldwide of requiring a total joint replacement.
- Associated problems:
  - Speech
  - Swallowing
  - Mastication
  - Appearance
  - Dentistry
  - Psychological impairments   (Roychoudhury *et al* 1999)

- Clinical Presentation:
    - Increasing pain with eating
    - Progressive limiting of mouth opening
    - Radiographic evidence of joint degeneration i.e. decreased joint space, osteophytes, surface erosion and ankylosis.

Indications

- Restricted mouth opening (<35mm)
- Dietary scores (Liquid scores – 0, Full diet scores – 10)
- Occlusal collapse (Anterior open bite or retrusion)
- Excessive condylar resorption and loss of vertical ramus height
- Pain VAS >5 out of 10.
- Quality of Life Issues (Sidebottom 2008)

(Felstead *et al* 2011)

Surgical correction of TMJ ankylosis

- Aggressive reduction of the ankylotic mass – **gap arthoplasty using an inter-positioning material to prevent recurrence.**
- Procedure:
    - Removal of a piece of bone, either the full condyle or a full thickness section of the condyle
    - The width and extent of bone removal is crucial: must be at least 1cm to prevent reankylosis
    - Ipsilateral and/or contralateral cornoidectomy may be necessary to achieve maximal mouth opening

Inter-positioning material (obliterates gap)

- Autogenous:
    - Temporalis muscle, very popular due to proximity to the operative site.
    - Masseter muscle
    - Fascia lata
    - Auricular cartilage

- Alloplastic inter-positional grafts (smaller success rate than autogenous grafts):
  - Silastic
  - Teflon
  - Metallic fossa implants
  - Acrylic marbles

TMJ Replacement

- Necessary where reconstruction of the condyle to prevent an open bite, establish posterior face height and avoid pseudoarticulation that may promote reankylosis.
- Autogenous:
  - Fibula
  - Metatarsal
  - Clavicle
  - Iliac crest
  - Sternoclavicular
  - Costochondral
- Alloplastic:
  - Acrylic
  - Compressible silicone rubber
  - Total Joint systems
- Costochondral rib graft is most popular: long-terms steroids may weaken the graft and lead to re-ankylosis, donor site morbidity may occur.
- Complications:
  - Scar formation
  - Facial nerve damage
  - Gustatory swelling
  - External auditory meatus damage
  - Perforation into the middle cranial fosse and sever bleeding

(Felstead *et al* 2011)

2.3 The Multidisciplinary Team

The Rheumatology MDT deals with the investigation, diagnosis, management and treatment of patients with AS, arthritis and other musculoskeletal conditions. The term 'musculoskeletal condition' incorporates over 200 disorders affecting joints, bones, muscles and soft tissues. While a large number of these conditions are confined to the musculoskeletal system, many of them, including AS, affect other organ systems. This makes their management more complex, requiring more efficient communication and co operation amongst the members of the MDT (Dziedzic and Hammond 2010). Recent studies have shown that a combination of biological treatment and physical therapy, occupational therapy, or multidisciplinary rehabilitation programs, gave synergetic effects and produced positive effects on pain, function, and health related quality of life (Dubey *et al* 2008, Spadaro *et al* 2008, Masiero *et al* 2011, Lubrano *et al* 2006).. The team involved with any one patient may grow and alter as a variety of specialist skills may be required at different times. One must remain aware that the patient is the most important member of the team. The patient knows what problems they are having and how these problems are affecting their daily lives (David and Lloyd 1999).

Diagram 2. The Multidisciplinary Team in Rheumatology
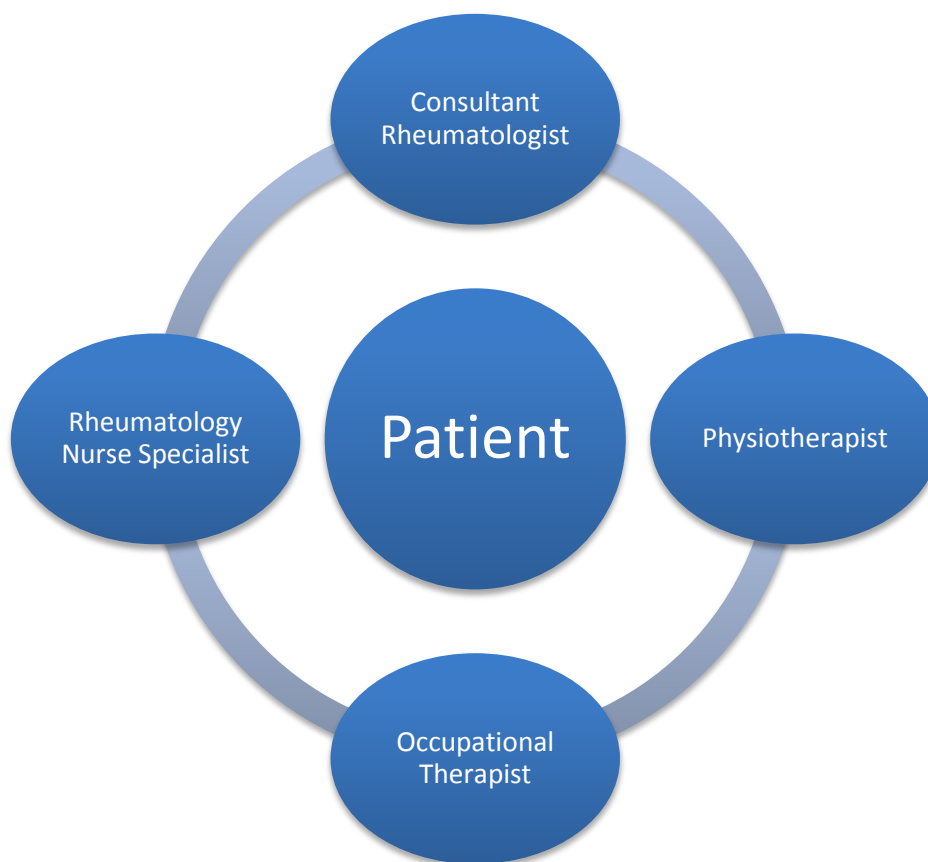
Table 11. Core Memebers of the Multidisciplinary Team
Patient and Carer
Rheumatologist
Physiotherapist
Occcupational Therapist
Nursing Staff/Rheumatology Nurse Specialist

Other disciplines that can be involved at different times include:

Table 12. Other Disciplines involved in the Rheumatology MDT
General Practitioner
Orthopaedic Consultant
Pharmacist
Chiropodist
Othotist/ Appliance Officer
Dermatologist
Social Worker
Clinical Psychologist

Table 13. The Role of the Consultant Rheumatologist
Diagnosis
Education
Reduce pain and discomfort
Control inflammation
Improve patient's QoL
Provide rapid and sustained symptom relief
Prevent/Stop disability
Treat co-morbodities
Administer appropriate therapy

Rheumatologists have general medical knowledge, and have additional training and experience in the diagnosis and treatment of arthritis, AS, and other diseases of the musculoskeletal system. The team approach to providing care is highly valued by rheumatologists because rheumatology manages longstanding and often incurable conditions (Dziedzic and Hammond 2010). The rheumatologist will confirm the diagnosis of AS, decide what initial treatment should be provided and oversee the long-term management of this

condition (NASS 2010). Rheumatologists undertake many practical procedures including joint aspiration, joint injection, ultrasound, nerve conduction studies, arthoscopies and muscle biopsies. Depending on the stage of the disease and the service provision in an area, patients may meet their rheumatologist yearly for monitoring or more frequently if in the early stages of diagnosis and treatment. AS is a complex rheumatic disease which the rheumatologist will monitor and assess over time by working closely with the patient and the rheumatology team.

Table 14. The Role of the Occupational Therapist
Education
Functional Assessment
Fatigue Management
Instruction in Joint Protection
Aids and Assistive Devices
Splinting
Education about Modification of Daily Activities
Return To Work Strategies
Modification of The Workplace
Energy Conservation Strategies

The occupational therapist's role is to improve patients' ability to perform daily tasks, help them adapt to disruptions in lifestyle and prevent loss of function.

The aims are to:

- improve their ability to perform daily occupations,
- facilitate successful adaptations in lifestyle,
- prevent losses of function and
- improve or maintain psychological status.

Principles of fatigue management, energy conservation and joint protection, as well as

techniques for stress management, are taught to minimise fatigue, reduce stress on joints and increase performance in the activities of daily living. Patients are trained in alternative methods and the use of adaptive equipment for performing daily self care, work, school, leisure and recreational tasks. (Clarke 2000). Interventions emphasise achieving empathetic rapport and providing counselling and support appropriate to the person's needs to explore the impact of disease on their lives and assist in adjusting lifestyle. Emphasis is placed on evaluating the patient within the context of his/her home, work or school setting so that appropriate, acceptable interventions will enhance the patient's capabilities. Environmental modifications may be necessary to promote independent functioning, e.g a toilet seat raise may allow someone remain independent with regard to toileting. Ergonomic positioning of desks, chairs and computer monitors may be important for patients in sedentary jobs. An occupational therapist may also help the patient adjust to new or changed roles in the family or community (Sparado *et al* 2008).

A key role of occupational therapists is providing education and equipment to enable a patient to employ energy conservation strategies. These can be remembered by the 4 P's:

1. Plan: Keep a diary so that you can plan the day's events.
2. Pace: Pacing includes the setting of realistic goals to increase activity gradually where appropriate (Swann, 2008).
3. Prioritise: Make prioritized lists of any necessary tasks.
4. People: Ask for help when required and delegate tasks to others.

Table 15. The Role of The Rheumatology Nurse Specialist
Assessment
Examination of Joints
Monitoring of Blood Results
Monitoring of Patient's Overall Condition
Education
Support and Advice

Many rheumatology nurse specialists (RNS) run nurse led clinics where they assess and treat patients, working closely with the consultant rheumatologist. Their work involves examination of the joints, assessment of patients' overall condition and monitoring blood results. They may be trained to carry out procedures such as examining joints, performing joint injections, reviewing and requesting investigations, and altering treatments (NASS 2010, Venkatachalam, 2010). RNS play a key role in counseling patients on disease-modifying drugs and their side effects. They objectively measure disease activity. They offer support and advice to help reduce fear and anxiety. They provide detailed explanations of diagnosis, drug therapies and other managerial strategies at the onset and throughout the course of the condition. They provide psychosocial support to the patient (Venkatachalam 2010). Education is another important element of their role and many RNS are involved in the development and running of rheumatology educational programmes for other members of the MDT. They may be involved in individual or group education and empower self-management (NASS 2010, Venkatachalam, 2010).

Rheumatology Service Provision in Ireland

There are twelve specialist rheumatology centres in the Republic of Ireland. These are located in Navan; five in Dublin; two in Cork; one in Limerick; one in Galway and one in Leitrim. There is one wholetime equivalent rheumatologu consultant per 400,00 of the population. However, the British Society of Rheumatology recommends that an adequate rheumatology service should consist of one wholetime equivalent consultant per 85,000 population. The access to MDT input varies greatly from centre to centre with some rheumatology centres providing more services than others. Mary Healy, of the Mayo Branch of Arthritis Ireland, reported that there is a nationwide shortage of consultants, physiotherapists, occupational therapists and specialist rheumatology nurses.

Interview with an Expert - Dr. Norelee Kennedy

1.What are the most commonly encountered problem in AS from a physiotherapy point of view?

'Managing pain and ADLs, understanding physiotherapy regimes'**.**

2. Most commonly overlooked problems?

'Psychosocial cosiderations such as work and employment, however this is very service dependent. There can be problems such as late referral to the right person and access to MDT intervention also'.

3. What your mainstay treatments are in AS?

'Exercise'.

4. What psychosocial issues you encounter most commonly in this patient group?

'Fear of the future, work issues, taking medication and driving'.

5. What are the main barriers/ issues to physiotherapy treatment you encounter?

'The practicality of fitting a physiotherapy programme into family and work time constraints'.

6. What your key piece of advice would be to new physiotherapist working with AS patients?

'Understand the conditon and the person experiencing it. Monitor AS symptoms regularly. Work with the patient to understand their lifestyle and how best that they can fit physiotherapy programmes into it'.

'A profile of Irish physiotherapy services for ankylosing Spondylitis (AS)'

Larkin *et al* (2011)

This study has explored the physiotherapy services provided to AS patients in the Republic of Ireland (ROI) via an online questionnaire distributed to the ISCPs Rheumatology clinical interest group (CPR) (n=29). The response rate was 45% (13/29).

The main findings were as follows:
- 88% (7/8) of those surveyed were aware of clinical guidelines for AS management.
- The Bath AS Scores were the most commonly utilised outcome measures– BASDAI (8/8, 100%), BASFI (7/8, 88%), BASMI and BAS-G (6/8, 75%).
- Home exercise programmes (8/8, 100%) were the most common treatment methods, followed by group exercise and advice to undertake regular physical activity (7/8, 88%), and hydrotherapy (6/8, 75%).
- Component of the HEPs are shown in the table below:

Table 16. Component of home exercise programmes (Larkin *et al* 2011)

*Note (x/n): (x) denotes the number of respondents providing this answer; (n) denotes the total number of respondents to the question, e.g. (3/8)

**ROM = Range of Motion
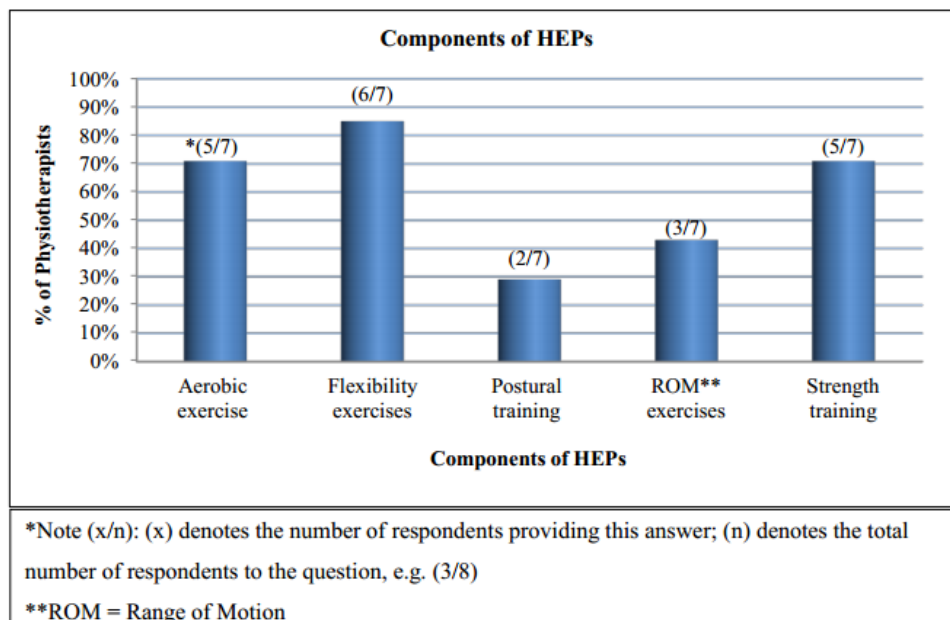
- All those surveyed said they incorporate patient education and promotion of self-management into management of AS patients while 75% (6/8) use strategies to improve motivation to exercise.

PHYSIOTHERAPY MANAGEMENT IN ANKYLOSING SPONDYLITIS

Overview:

The physiotherapist has a key role in the management of Ankylosing Spondylitis.

The aims of physiotherapy in this population include:

- reducing pain and discomfort;

- maintaining &/or improving muscle strength and endurance;

- maintaining &/or improving flexibility, mobility and balance;

- maintaining &/or improving physical fitness, physical function and thereby social participation and overall QOL;

- preventing where possible spinal curve abnormalities and joint deformities.

(Ozcogmen *et al* 2012; Zochling *et al* 2006)

The importance of this role is noted in the updated ASAS/EULAR recommendations for the management of Ankylosing Spondylitis (Braun *et al* 2011). This highlights physiotherapy involving '*patient education and regular exercise*' as the cornerstone of non-pharmacological treatment in AS (Braun *et al* 2011).

In line with this the following section will discuss the physiotherapist's role in AS with considerations for physiotherapy management also identified and addressed.

2.4.1 <u>Exercise Prescription in Ankylosing Spondylitis:</u>

Although exercise is strongly recommended in AS, there are <u>no guidelines</u> available which outline the optimum FITT principles for exercise prescription in this population.

The ACSM does have exercise recommendations for persons with chronic diseases and disabilities (2009) however these are not specific to AS.

In light of this, the following sections will present the most recent literature describing the different types of exercise included in programmes for AS e.g. aerobic, resistance, flexibility components etc. with the aim of establishing a FITT principle for this population.

However as always, exercise should always be tailored for each patient taking into account:

- Current manifestations of their condition e.g. axial, peripheral, entheseal, extra-articular signs and symptoms.
- Level of current symptoms, findings on clinical examination and overall prognostic indicators:
  - Disease activity/inflammation and inflammatory markers
  - Pain rating
  - Functional difficulties and disability
  - Structural damage, spinal deformities, hip involvement.
- Overall clinical picture (age, gender, any co-morbidities, concurrent medications, psychosocial issues).
- Patient's own goals and expectations of physiotherapy.   (Braun *et al* 2011)

Pre-exercise:

In the interest of patient safety, clearance from the GP/Rheumatologist should be sought prior to starting any exercise programme.

This is particularly important if:

- The patient has had any spinal surgery or joint replacement surgery as the programme may need to be modified.
- The patient has any other medical conditions, especially those effecting the heart or lungs and/or is on any medication for their heart or blood pressure.
- The patient reports any chest pain, palpitations, unexplained breathlessness, dizziness, or loss of consciousness
- The patient is pregnant
- The patient is experiencing a flare-up.
- The patient is not used to exercise.
- The patient is aged ≥ 65 years or have had AS for ≥10 years

(National Ankylosing Spondylitis Society 2012)

During exercise:

Patient should be advised to seek medical advice if they experience any unexplained symptoms during exercise such as:

- ❗ Chest pain or palpitations
- ❗ Sudden/unexpected shortness of breath
- ❗ Dizziness
- ❗ Fainting/Loss of consciousness
- ❗ Sudden general unwellness   (NASS 2012)

Post exercise:

Patients should be warned that they may experience some mild aches and pains during and post exercise. This pain should not be prolonged or severe. If the patient does experience anything more than mild aches and pains that do not ease post-exercise, they should stop and seek professional/medical advice.

COMPONENTS OF EXERCISE PROGRAMME:

2.4.2 Posture:

Postural education is of critical importance: In our role as educators we must ensure patients have an excellent understanding of good posture and neutral spine.

This can be achieved by:

Giving a verbal explanation as well a practical demonstration of same during sessions.

Giving patients constant verbal feedback as well as using visual feedback aids such as mirrors, cameras, videotaping.

Clinical Practice Point!
Remember if the spine has lost ROM, it may not be possible to get back to a neutral position.

Patients should be encouraged and prompted to maintain good posture during ALL exercises.

2.4.3 <u>Aerobic Exercise</u>

Patients with AS have been shown to have lower cardiorespiratory fitness when compared with population controls (Carter *et al* 1999; Halvorsen *et al* 2012; Ozdem *et al* 2011) with this reduced cardiopulmonary fitness linked to reduced exercise tolerance (Ozdem *et al* 2011). Therefore it has been recommended that cardiorespiratory exercise be included as a basic component of the physiotherapy programme to improve vital capacity (Ozdem *et al* 2011), physical fitness and endurance (Ozgocmen *et al* 2012) and also as a basic component to reduce the risk of cardiovascular disease (Halvorsen *et al* 2012).

A literature search revealed a number of studies which included some form of aerobic exercise in their intervention however many of these failed to assess aerobic capacity as an outcome measure. For this reason only the three studies outlined overleaf were selected for review. The quality of these studies varied with Karapolat *et al* (2009) having the lowest risk of bias.

Results of these trials suggest that any form of aerobic exercise impacts positively on aerobic capacity in AS with improvements in VO2max and exercise stress test performance recorded when aerobic exercise was performed for 30 mins, 3 times a week at low-moderate intensity (Analay *et al*, 2003; Ince *et al*, 2006; Karapolat *et al*, 2009). Improvements were also noted in measures of functional performance and psychosocial wellbeing (Analay *et al* 2003; Karapolat *et al*, 2009). However it must be noted that all these studies involved multi-modal programmes as opposed to aerobic exercise alone.

Also all used low-moderate intensity exercise. High intensity exercise has not been widely evaluated mainly due to the excessive stress its places on the heart in a population whereby there is already a high incidence of cardiac problems. Ince *et al* 2006 deemed it may be unnecessary to use high intensity exercise because as illustrated in these studies working at both low and moderate intensity proved significantly beneficial in increasing aerobic capacity while not unduly stressing the cardiovascular system.

Table 17. Evidence for Aerobic Exercise

Study	Subjects	Intervention				Outcome	Results	Strengths/Limitations of Study
		Type	Intensity	Time	Freq			
Analay et al 2003	N=45 Group 1: n=23 mean age 37.6yrs. Group 2: n=22, mean age 34.3yrs. 38 M: 7 F	Group 1: Intensive supervised group exercise inc. Static cycling Group 2: HEP based on group exercise program + weekly phone call Both groups received educational session prior to program.	Not clear, cycled against no resistance however.	Session duration: 30 mins Intervention duration: 6weeks	3days/week	Vo2max: @ baseline, post intervention & 3mths. Selected others: Pain at rest and during activity with VAS Beck Depression Scale, BASFI	Group 1: Vo2max ↑ w/ results maintained @ 3mths. Group 2 ↓ aerobic capacity post-intervention & @ 3 mths.	Risk of bias- Moderate Double-blind, randomised trial Blinded assessors, allocation concealment. High drop-out rate. Intensity of aerobic exercise not controlled. No intent-to-treat & point estimates NOTE: Aerobic exercise only one part of multi-modal program.
Ince et al 2006	N=30 Exercise group: n=15, mean age 36 yrs. Control group: n=15, mean age 34 yrs. 18M: 12 F	Multi-modal supervised exercise program: including aerobics (17 lower limb activities). + usual medical care Control group: usual medical care.	Generally low intensity. Personalised low intensity target zones set using Karvonen formula. A metronome & Borg scale were used to support the Karvonen formula.	Session duration: 30 mins. Intervention duration: 12 weeks	3days/week	PWC 170 test- Bicycle exercise test. Vital Capacity (VC) Chest expansion Flexibility measures	Exercise group: Statistically significant ↑ in PWC170 test (p=0.001) with VC unchanged Control group: Stat. sign. reduction in PWC170 test (p=0.002) & VC (p=0.004) Other Outcomes: Significant improvement in chest expansion & flexibility measures	Risk of Bias- High Exclusion criteria not described. No allocation concealment. Drop outs and losses to follow-up not accounted for with no use of intent-to-treat analysis. No point estimates. Also the control group had a higher baseline PWC170 score. NOTE: Aerobic exercise only one part of multi-modal program.
Karapolat et al, 2009	N=37 Group 1: n=13, mean age ≈50yrs. Group 2: n=12, mean age ≈47yrs. Group 3: n=12, mean age ≈48yrs. 27 M:10 F	Educational session & individual counselling for both groups. Group 1: conventional exercise & swimming Group 2: conventional exercise & walking Group 3: Conventional exercise	Swimming & walking @ 60-70% HRR or 13-15 Borg scale. Conventional exercise: intensity not specified	Swimming & walking session duration: 30 mins Conventional ex session duration: 30 mins. Intervention duration: 6 weeks	Swimming & walking 3days/week Conventional exercise 6days/week	Vo2max 6 MWT Nottingham Health Profile (NHP)	Group 1 & 2: Significant ↑ in Vo2max & 6MWT (p<0.05). Group 3: Non significant ↑ in Vo2max. 6MWT ↓ Other outcomes: Stat. signif. improvement in energy, emotional reaction & physical mobility sub-scores of NHP in all groups post- inter	Risk of bias- Low Blinding of assessors is not mentioned. Small number of drop outs.

2.4.4 <u>Strengthening Exercise:</u>

Exercise to maintain or improve muscular strength is recommended to be included as part of the physiotherapy programme for AS patients (Ozgocmen et al 2012). However there is a paucity of evidence in the area of strength training in AS with only three studies of low/moderate quality included for review. These studies outlined in the overleaf included strengthening of the lower and upper extremities and back extensors aswell as targeted strengthening of postural muscles. The specifics of the strengthening programmes were poorly described in general with none of the trials including outcome measurement of strength variables. Also none of the trials met the ACSM recommendations for developing muscular strength and there was no use of external load in any of the trials indicating programmes were of low resistance (Dagfinrud *et al* 2011).

Despite the scarcity of quality evidence in this area, the rationale behind the inclusion of resistance/strength training in AS remains. The aims of inclusion of resistance/strength training are as follows:

1) To strengthen muscle groups to maintain good posture and postural alignment. This is in line with EULAR/ASAS recommendations for physiotherapy whereby aims include not only improving strength but preventing spinal curve abnormalities and spinal and joint deformities (2010).

2) To support bone health considering the prevalence of osteoporosis in AS populations (El Maghraoui 2004)

3) To counteract deconditioning in AS which can affect exercise tolerance, aerobic capacity and functional capacity in this populations (Carter *et al* 1999; Marcora *et al* 2006). This deconditioning may be linked to the cachexic processes occurring in the background of chronic inflammation and risk of reduced physical activity in AS (Kotler 2000) and may also be linked to steroid related myopathy secondary to long-term steroid use.

Table 18. Evidence for Strengthening Exercise

Study	Participants	Interventios				Outcome	Results	Strengths/Limitations of Study
		Type	Intensity	Time	Freq			
Analay *et al*, 2003	N=45 (38 M: 7 F) Group 1: n=23 mean age 37.6yrs. Group 2: n=22, mean age 34.3yrs. Inclusion criteria: AMOR criteria, able to participate in ex. group Exclusion criteria: systemic organic involvement, hip/knee deformities, physio in last 3mths or regular exercise, receiving DMARDS	Group 1: Intensive supervised group exercise program, inc. strengthening exercises for lower, upper extremities, back muscles as part of overall program, Group 2: HEP based on group exercise program. + weekly phonecall Both groups received education	-	Session duration: 30 mins Intervention duration: 6weeks	3 times/wk	Pain at rest and during activity with VAS Beck Depression Scale, BASFI	Statistically significant improvement in Beck & BASFI scores (p<0.05) immediately post-treatment but difference in Beck scores disappeared at 3mths. No change to pain levels.	Double-blind, randomised trial Blinded assessors, allocation concealment. High drop-out rate. Poor description of strengthening exercises. No strength outcome measurement, <u>NOTE:</u> Strengthening was only one part of the exercise program which included stretching, mobilization and strengthening exercises, aerobic exercises and postural and respiratory exercises
D'Las Penas *et al*, 2005	N=40 Group 1: n=20 Group 2: n=20 78% men, mean age 45.5 yrs. Inclusion criteria: NY criteria Exclusion criteria: functional class level IV, comorbidity, OP.	Group 1: Global Postural re-education involving targeted strengthening of muscle chains involving shoulder, legs and abdominals. Group 2: Supervised classes, flexibility, stretching and chest expansion exercises.	8-10 reps, no external load	Session duration :1 hour Intervention Duration: 4months	1 per week	BASMI BASFI BASDAI	Both groups improved in BASDAI. Group 1 showed statistically significant improvement in BASMI (p<0.01) & BASFI scores (p = 0.03).	Blinded assessors and allocation concealment. Exclusion or losses to follow-up unclear. No strength outcome measurement.

*** 1 year follow-up of the above study noted: that improvements in all mobility measures of the BASMI index and in the BASFI index were partially maintained at the 12-mo follow-up in the experimental group but not in the control group.*

Lim *et al*, 2005	N = 50 Group 1: n = 25 Group 2: n = 25 Inclusion criteria: outpatient without complications, no regular exercise in 6 mths prior, ability to understand questionnaires, no medication changes, classified functional class II for AS Exclusion criteria: Not described	Group 1: Home-based exercise program Group 2: 8 week waitlist period	Uncle ar	Session duration : 30 mins Interven tion duration : 8 weeks	7 times/ wk	BASFI Beck Depress ion Invento ry	Statistically significant decreases in pain (p<0.01) & depression (p<0.01) & increase in functional capacity & joint mobility in exercise group (p<0.01).	Poor description of exercise intensity No strength outcome measurement. Allocation concealment unclear. NOTE: Strengthening only one part of the exercise program.

2.4.5 <u>Flexibility Exercise</u>

Stiffness and reduced mobility have already been outlined as primary characteristics of AS. Evidence based recommendations suggest the growing importance of physiotherapy interventions in tackling the issue of decreased flexibility and spinal mobility in peoples with AS (Zochling 2006). It has been noted that both spinal and peripheral joint mobility are prognostic indicators of AS disease progression (Calin 1987). This suggests the importance of both measuring joint mobility and incorporating flexibility exercises into one's exercise regime. Evidence is limited in understanding the effect of flexibility exercises alone on joint mobility in AS. However, there is an abundance of literature in the area of multi-modal exercise programs incorporating flexibility components to their program. A systematic review in 2011 (Dagfinrud et al), looked at physiotherapy interventions for AS and the effectiveness of these interventions. 11 out of 12 trials in this study incorporated flexibility exercises into their exercise programs. However, the descriptions of the flexibility components were both limited and/or missing in all of these trials.

Flexibility exercises are performed as either dynamic exercises or stretching. Dynamic exercises in the studies mentioned below include back exercises primarily with some studies looking at the whole body dynamically. The table below takes a closer look at some of the trials in this study by Dagfinrud et al in 2011 and the effectiveness of flexibility exercise in people with AS. The table also contains studies already discussed in the aerobic and strengthening sections. Therefore, the study content can be found in these sections.

Table 19. Flexibility Studies and their effectiveness.

Study	Repetitions	Stretch Duration (seconds)	Frequency (days/week)	Program Duration (weeks)	Physiological Response (Spinal Mobility)
Analay et al 2003	NR	NR	3	6 weeks	Supervised: FFD ES 0.38 Schober test ES 0.31 Unsupervised: FFD ES 0.05 Schober test ES 0.24
Fernandez-de-Las-Penas et al, 2005	1-2	45 seconds to 4 mins	1	16 weeks	Program 1: Schober test ES 0.15 Program 2: Schober test ES 0.46
Cagliyan et al 2007	NR	NR	2	12 weeks	Supervised: FFD ES 0.67 Schober test ES 0.58 Unsupervised: FFD ES −0.02 Schober test ES −0.08
Ince et al 2006	NR	NR	3	12 weeks	Exercise group: FFD ES 0.21 Schober test ES 0.11 Control group: FFD ES −0.04 Schober test ES −0.24

(NR= Not Reported, FFD= Finger to Floor Distance, ES= Effect Size, BASMI= Bath Ankylosing Spondylitis Metrology Index).

Table 20: Evidence for Flexibility Exercises (excluding Analay et al 2003, Fernadez-de-Las Penas et al 2005 and Ince et al 2006. See table 17 &18).

Study	Subjects	Intervention	Outcome Measures	Conclusion	Strengths and Limitations
Cagliyan et al 2007	46:38(M), 8(F) Mean age: 37.5 years	As in table 19 with joint ROM and flexibility exercises of the cervical, thoracic and lumbar spine. Also strengthening, respiratory and postural exercises.	BASMI BASFI BASDAI	Hospital exercises showed better improvements in spinal ROM, depression and QOL. Home based exercises had improved in spinal activity.	Small sample size. No significant changes in BASMI scores Assessors not blinded. Evaluation carried out by same assessors as at the 3 and 6 month post treatment

2.4.6 <u>Respiratory Exercises</u>

Bony ankylosis can occur in the joints the thorax, causing limitations in movement of the chest wall (Fisher et al 1990). The typical picture of respiratory status for people with AS is that of a restrictive defect (Fisher et al 1990). There is evidence to suggest that this limitation in chest wall expansion is associated with a reduced vital capacity (Feltelius et al 1986). Although there has been no direct correlation between exercise tolerance and chest wall expansion in people with AS, there has been evidence for a correlation between chest wall expansion and vital capacity (Fisher et al 1990). This final correlation suggests the importance of respiratory exercise and improving spinal mobility in not only maintaining chest wall expansions and respiratory function but also in order to maintain good cardiorespiratory fitness.

Evidence for respiratory specific exercise programs is limited. The review by Dagfinrud in 2011 describing the effectiveness of exercise programs in peoples with AS does not look at the effect of respiratory exercises despite some of their studies including a respiratory component. This supports the noted limitations observed.

One of the first studies to include respiratory exercises and actively measure their outcome in terms of a respiratory specific measure was (Durmus et al 2009). This study is outlined in the table below in further detail.

As a whole, studies that incorporate respiratory exercises do so in a multi-modal approach. The following exercises are an example of exercises that can be incorporated into a multimodal approach and have illustrated improvements in chest wall expansion and functional capacity (Ince et al 2006):

- twice the normal rate of inspiration through the nose and expiration through the mouth
- normal expiration through nose and normal expiration through mouth
- respiration through the chest and abdomen
- deep breathing and then expiration through the mouth slowly
- resistance exercises for inspiratory pulmonary muscles

The next two tables outline studies that incorporate a respiratory component.

Table 21. Effects of two exercise interventions on pulmonary functions in the patients with AS (Durmus et al 2009)

Study	Intervention	Outcome measures	Conclusion	Strengths/ Limitations
Effects of two exercise interventions on pulmonary functions in the patients with AS **56 subjects** **Male: 43** **Female: 13**	**Activity:** **Group 1:** ROM and flexibility Exercises Cx, Tx, Lx; stretching: erector spine, hamstring, shoulder, chest expansion, controlled abdominal and diaphragm breathing. **Group 2:** GPR: stretching posterior/anterior muscle chain, pelvic gliding, McKenzie method, respiratory exercises **Intensity:** Not given **Frequency:** Not given **Duration:** Daily for 12 weeks	BASFI BASDI chest expansion, FVC, FEVI, PEF, VC, MVV and 6MWDT	GPR maybe more effective than conventional exercise in pulmonary function tests such as FVC; FEVI and PEF	Non-randomized control trial; limited information given regarding intervention, exercise compliance not assessed, small sample size: no details on participant recruitment given,

Table 22. The effect(s) of a six week home-based exercise program on the respiratory muscle and functional status in AS (Ortanical et al 2009)

Study	Intervention	Outcome Measures	Conclusion	Limitations
The effect(s) of a six week home-based exercise program on the respiratory muscle and functional status in AS **22 subjects**	**Activity:** Breathing exercises and upper extremity exercises **Intensity:** Not given **Frequency:** Not given **Duration:** Daily for 6 weeks	Chest expansion, tragus-wall distance, maximal inspirations pressure, maximal expiratory pressure, 6mwdt; physiologic cost index BASFI,	HEP can have effect on some measures of respiratory muscle and functional status	Non-randomized controlled trial. Small sample size, no exercise compliance assessed, prospective study.

2.4.7 Spa Therapy

What is it?

It is the use of water for medical treatment by means of bathing in thermal water. It is generally carried out in a "holiday environment".

(Van Tubergan *et al* 2001)

What does spa therapy involve?

Originally spa therapy consisted of the use of hydrotherapy and balneotherapy but it now incorporates four key modalities (Bender *et al* 2005).

Climatotherapy

Climatotherapy involves the treatment of disease in an area with a favourable climate. Climatotherapy has been shown to be significantly beneficial for patients with inflammatory arthritis. However, further research is required to gauge information on sustained effects and effects on work and hospitalisations (Hashkes 2002).

Climatotherapy at the Dead Sea area has been shown to be beneficial for AS patients with long-standing disease regarding outcomes such as disease activity, pain, quality of life and spinal movement (Codish *et al* 2005).

A more recent study concluded that physiotherapy for AS was more beneficial in a warmer climate (compared to usual treatment at home). While both groups showed improvements, the improvements were greater and more effectively sustained in the warm climate group. Improvements were noted in spinal mobility, physical capacity and health status (Staalesen Strumse *et al* 2011).

Hydrotherapy

Hydrotherapy is the utilisation of exercises in water. The warmth and buoyancy of the water allows for muscle relaxation and the reduction of the weight-bearing load on the trunk and lower extremities. The water is also employed as a method of exercising more successfully by means of an increase in resistance to movement.

It is carried out in a specific hydrotherapy pool setting under the direct supervision of a trained health professional.

(Bender *et al* 2002, Cochrane et al 2005, Fransen et al 2007)

Mechanism of Action

- Buoyancy
- Immersion
- Resistance
- Temperature

Pain Gate Theory: pain relief due to *pressure* and *temperature* on skin (Melzack *et al* 1965).

Water immersion: increased levels of methionine-encephalin in the plasma and reduced levels of plasma β-endorphin, corticotropin and prolactin (Coruzzi *et al* 1988).

Muscle relaxation and reduced joint swelling may also play a role. Enhanced mood and improved tension may also influence results (Hall *et al* 1996).

Group therapy is more effective than individual sessions due to the increased focus on well-being and improvements in health rather than on disease as a result of the social interaction involved (Reilly *et al* 2001).

Balneotherapy

Balneotherapy differs from hydrotherapy in that it uses natural thermal (temperature greater than twenty degrees Celsius) mineral waters rather than simple water. The amount of the minerals present in the water must be insignificant and the water must also be free of bacteria.

Mechanism of Action

- Absorption of minerals through skin: little evidence

- Vasodilatory effect of heat: this mechanism eradicates allogenic substances (substances which promote the production of antibodies) from affected areas. There is stimulation of the type Ib fibres and golgi tendon organ reflex which results in reduced muscular activity leading to muscle relaxation. This may also harbour the consequence of an indirect analgesic effect (Altan *et al* 2006).

- Pain-gate theory: achievement of a general sedative effect as a result of pain perception being blocked at the level of the dorsal horn as a result of the thermal stimulus (Melzac & Wall 1965).

Active exercise/Massage/Mud-Packs/Electrotherapy:

Active exercise

Shown to be effective for AS patients when used as part of the spa therapy regime (group physical exercises, walking, correction therapy, hydrotherapy, sports, Climatotherapy). (Van Tubergen *et al* 2001). *See "Exercise" section of handbook for further information on this topic.*

Massage

Currently, there is no evidence of effect of massage for AS

Mud-packs (as part of combined spa therapy)

Shown to be beneficial for AS patients when used at a specialised spa centre.

The application of heated mud-packs (40-45 degrees Celsius) promotes the increase in joint mobility and muscle relaxation. There may also exist an anti-inflammatory effect of mud-packs as the vasodilation that occurs increases tissue blood-flow, exerts this effect and consequently removes numerous pro-inflammatory substances e.g. free radicals, from the involved tissues (Schmidt 1991).

Electrotherapy & Manual Therapies

Currently, there is no evidence of effect of either for AS.

Placebo effect of Spa Therapy

It is believed that there is a definite placebo effect associated with spa therapy. Namely due to beliefs regarding improvements gained as a result of spa therapy and the positive attention experienced for the duration of the therapy. The change in environment in combination with the absence of work duties may also contribute to this placebo effect. It would be assumed that this placebo effect would quickly disappear once the therapy had ended. However, the results of an RCT conducted by *Van Tubergan et al* (2001) noted an increasing improvement at sixteen weeks post-intervention. This indicates specific effects of the intervention rather than placebo alone.

Cost-effectiveness of Spa Therapy for AS

Van Tubergen *et al* (2002) conducted a study investigating the cost effectiveness and cost utility of combined spa-exercise therapy for AS patients. In the study, a 3-week combined spa-exercise therapy intervention was considered. This was in conjunction with standard treatment (NSAIDs) and weekly physiotherapy group sessions. There were 111 patients involved in the study. Both direct and indirect costs were accounted for.

There were three groups in the study. Two groups attended spa resorts, one in Austria and one in The Netherlands. The final group remained at home and continued usual treatment. The total study period was 40 weeks.

The conclusion of this study was that the combined spa-exercise therapy approach, in addition to regular medical and physiotherapy intervention is more effective and displays positive cost-effectiveness and cost-utility ratios compared with standard treatment alone in patients with AS.

2.4.8 Other Exercise Modalities

Fernadez-De-Las-Penas' GPR (Global Postural Re-education) Method

This exercise program for people with AS was introduced in 2005 by Fernadez-De-Las-Penas *et al*. It has since been included in other studies examining the effect of exercise regimens in people with AS on varying outcome measures, such as in the study by Darmus et al 2009.

The GPR programme, when focused with the muscle chains that mostly affect AS, has proven to generate greater improvement in functional and mobility outcomes than those patients who received a conventional regimen of analytic exercises

So what does the GPR method comprise of?

It employs specific strengthening and flexibility exercises in which the shortened muscle chains are stretched and strengthened.

These exercises are:

General warm-up: stretching exercise of the posterior muscle chain, stretching exercise of the anterior muscle chain, and neural mobilization of the median nerve,

Specific warm-up: antero-posterior pelvic girdle gliding, extension flexion motion of the lumbar spine (McKenzie method), stretching exercise of the anterior muscle chain in the pelvic region, and stretching exercise of the posterior muscle chain in the pelvic region,

Dynamic axial exercise: prone exercises, anterior pelvic girdle gliding, antero-posterior pelvic girdle gliding in supine, rotation stretching of the posterior muscle chain,

Static postural exercise: stretching exercise of the anterior muscle chain in supine, stretching exercise of the posterior muscle chain seated, stretching exercise of the posterior muscle chain seated on the wall, stretching exercise of the anterior muscle chain standing, and eccentric work of the erector spine muscles,

Specific respiratory exercises: thoracic breathless, expiratory breathless, and stretching of the antero-internal muscle chain of the scapular girdle,

Cool down: cervical flexoextension, cervical lateral-flexion, cervical rotation, and circular motion of the scapular girdle.

The GPR method results in greater improvement with a group physical therapy program than with home exercises. This can be explained by the mutual encouragement, reciprocal motivation, and exchange of experience in group therapy (De-las-Penas et al 2005)

<u>Pilates</u>

While Pilates exercises mostly take place in training programs designated for healthy people as part of general fitness programs, it has recently been suggested as a therapeutic modality for several musculoskeletal disorders and chronic conditions (La Touche, 2008). Pilates training is intended to improve balance, strength, flexibility, posture, mobility, produce longer and leaner muscles, increase core strength, help prevent injury and enhance functional ease of movement. Very few clinical trials have been conducted on the effect of Pilates on people with AS.

Altan *et al* (2011) conducted the first and only RCT in this area, investigating the effect of Pilates on pain, functional status, and quality of life in 55 patients with ankylosing spondylitis (see table 1). In this randomized, controlled and single blinded trial, they examined the effect of a Pilates exercise program for 12 weeks on a group of AS patients compared with standard physiotherapy treatment for the control group. Functional capacity was the primary outcome measure used. In The Pilates group functional capacity as measured by the BASFI, showed significant improvement at week 12 ($P = 0.031$) and week 24 ($P = 0.007$) while in the control group this parameter was not found to have changed at week 12 or week 24.

Comparison of these two groups showed significant improvement in the Pilates group at 24 week, but no statistically significant difference between the two groups at 12 weeks, suggesting that the beneficial effect of Pilates exercises has been evident in the longer term.
As this is the first study clinical study designed to investigate the role of Pilates in AS, further research with more participants and longer follow up periods are needed to assess and clarify the therapeutic value of this popular exercise method in AS.

Table 23. Effect of Pilates training on people with Ankylosing Spondylitis (Altan et al 2011)

Study	Subjects	Intervention	Assessment	Results	Comments
Altan et al (2011) Effect of Pilates training on people with AS RCT	n=50 Dx with AS according to modified New York Criteria G1: n = 30 Pilates Training G2: n = 25 Previous Standard physiotherapy Rx	G1: Pilates programme for 1 hour, by certified instructor, 3 times a week, for 12 weeks. G2: Previous standard treatment programmes. Instructed to continue with their normal physical activity.	Assessed at baseline (0 weeks) Immediately post rx (12 weeks) 12 weeks post rx. Measures used: BASFI BASDAI BASMI Chest Expansion ASQOL	G1: Significant improvement on BASFI at week 12 & 24. (P = 0.031) (P = 0.007) Significant improvements with BASMI, BASDAI, chest expansion at 12 weeks. G1: No improvement in group 2 for any parameters at 24 weeks.	Effect of Pilates on As showed improvement in functional capacity for up to 6 months. No significant difference between groups at 12 weeks but at 24, suggest benefits of Pilates may more be evident in the long term. Limited info on rx of control group. Small participant number & relatively short follow up period.

Tai Chi

Tai chi is a combination of physical exercise and a relaxation technique rooted in ancient Chinese philosophy and is used to enhance its practitioners' mental and physical health.

Tai Chi is practiced as an exercise to promote good health, memory, concentration, digestion, balance, and flexibility and is also thought to improve psychological conditions such as anxiety, depression, and declines associated with aging and inactivity. It is also practiced to improve quality of life (Wang et al 2004).

Lee et al (2007) conducted a randomised controlled trial investigating the effects of Tai Chi on disease activity, flexibility and depression in patients with AS. 40 participants were randomly allocated to the Tai Chi group (n = 20) or the control group (n = 20). Subjects in the Tai Chi group attended 2 group tai chi classes per week for 8 weeks. The classes lasted for 45 minute and consisted of a 10 minute warm up, 30 minutes of 21 various tai chi movements and a 5 minute warm down. Similar to the intervention group the control subjects

received standard drug treatment provided by the outpatient clinic however they did not receive any other treatment and did not participate in any structured exercise programme.

Subjects in the Tai Chi group showed significant improvement in relation to disease activity and flexibility after 8 weeks compared to the control group. These results support previous findings in a systematic review by Wang et al 2004, that tai chi benefits flexibility and disease activity in various chronic conditions. Depression scores improved in the Tai Chi group also after 8 weeks compared to the control group, but changes were not significant. These results suggest tai chi improves flexibility and positively influences levels of disease activity in AS patients. However further randomized studies with more objective measures, larger samples and long term follow ups are needed to verify the effects of Tai Chi on people with AS.

Table 24. Tai Chi for Disease activity and flexibility in patients with Ankylosing Spondylitis – A controlled clinical trial (Lee et al 2007)

Study	Subjects	Intervention	Assessment	Results	Comments
Lee et al 2007 Tai Chi for Disease activity and Flexibility in patients with Ankylosing Spondylitis RCT	N=30 Dx with class 2 AS according to modified New York Criteria G1: n=13 Tai Chi Training G2: n=17 Control Group, No structured exercise programme	G1: Tai Chi consisted of 2 group *tai chi* classes, 2 times per week, for 45 minutes, for 8 weeks. Subjects were asked to practice the exercises at home once daily for 6 weeks and twice daily for final 2 weeks also. G2: Normal drug treatment but did not participate in any structured exercise programme during the 8 weeks.	Primary outcome Measure was disease activity BASDAI Secondary outcome measures were flexibility and depression measured by FFD and CES-D respectively. Subjects were measured at baseline (0 weeks) & immediately after rx (8 weeks).	G1: BASDAI and FFD had improved significantly to control group after 8 weeks rx, (P<0.05) & (P<0.05) respectively. G2: No significant intergroup differences were seen in depression scores.	Effects of *tai chi* on AS showed significant improvements in disease activity and flexibility after 8 weeks. No follow up measures. No improvements for depression scores. Small sample size, high dropout rate, Lack of equivalent exercise control group.

Exercise Setting: Home vs. Group Intervention:

In terms of the exercise setting, a Cochrane review of the evidence carried out by Dagfinrud *et al* (2008) concluded that although both home-based and supervised exercise programmes are better than no intervention, supervised group interventions are superior to home exercise programmes. This review also suggested that the most effective setting involves combined inpatient spa-exercise therapy followed by group physiotherapy (Dagfinrud *et al* 2008). A review carried out by Wang et al (2009) supported the efficacy of combined spa-therapy and group physiotherapy however, it recommended home exercise programmes as being most convenient, and therefore, first choice for AS patients. Provided patient adherence to home programmes remains high the benefits from home exercise alone and home exercise combined with weekly supervised group exercise are similar (Karapolat et al 2007 cited in Wang et al 2009). Home exercise is also more economical and efficient (Karapolat et al 2007 cited in Wang et al 2009).

Section 3 Considerations For Physiotherapy Management:

3.1 Fatigue

> *'No amount of sleep will reduce the fatigue that makes me feel like I'm walking around all day with one of those lead aprons that they use at the dentist's office for x-ray protection. It feels like when you experienced a bad case of the flu- pre AS.'*
>
> *Tim*
>
> *'Some days it feels like wanting to blend into the sofa, so that none of my family members will notice that I am there and ask or expect me to do anything.'*
>
> *Christie*
>
> (Spondylitis Association of America, 2006)

Fatigue is a common problem in patients with rheumatological conditions (Belza 1995; Da Costa *et al* 2004) with more than half of all people with AS reporting that fatigue as being a major concern for them (Jones *et al* 1996; Dernis-Labous *et al* 2003; Da Costa *et al* 2004).

Defining Fatigue:

It is important to define how fatigue differs from what is considered normal tiredness. Fatigue has been defined as an:

> "uncommon, abnormal or extreme whole bodily tiredness which is not related to activity or exertion",

While tiredness has been described as a:

> "universal sensation that is expected to occur normally at certain times of the day or after certain types of activity or exertion"　　　　(Carrieri-Kohlman *et al* 1993).

Mengshoel (2010) also identified two different conditions of fatigue and tiredness:

1. Life strain-related tiredness: which was considered to be comprehensible, manageable, and therefore natural in the sense that the tiring situations and recovery strategies were familiar to them and similar to their prior experiences as healthy individuals. Life strain related tiredness and recovery can be liked to daily life situations.

2. Illness-related fatigue: which can occur unexpectedly, with no understandable reason, and cannot be relieved by the usual self-management strategies

Consequences of Fatigue:

Fatigue is associated with increased pain (Jones *et al* 1996; Dagfinrud *et al* 2005; Hammond 2010), impaired cognitive functioning (Da Costa *et al* 2004, Dagfinrud *et al* 2005; Hammond 2010) and impaired physical functioning (Jones *et al* 1996, Da Costa *et al* 2004, Van Tubergen *et al* 2002). It is also linked to worsened psychological state (Hammond 2010) and is used as a measure of disease activity (Garrett *et al* 1994).

It can also have debilitating effect on a person's social life and on their vocation. In a recent qualitative study carried by Farren et al (2013) in this area, participants revealed that fatigue 'inhibited or limited social and leisure activities and engagement with family and friends.' Four of the ten participants from this study also stated that fatigue contributed towards their early retirement or was the cause of a change in employment (Farren *et al* 2013).

Finally from a physiotherapy point of view, fatigue is as an obstacle to exercise (Sundström *et al* 2002), and can inhibit physio management programmes (Farren *et al* 2013).

Table 25. Causes of Fatigue (Hammond 2010; Farren et al 2013)

Physical	Psychosocial	Environmental
• Pain • The disease (e.g. inflammation, especially in a flare up) • Physical demands due to biomechanical disruption of joints • Anemia (due to the disease, medication or other health/diet reasons) • Poor sleep (due to pain or stress) • Deconditioning • Overdoing activities (boom-bust cycle) • Poor nutrition (Caused by loss of appetite due to medication or difficulty cooking and shopping)	• Depression, anxiety, helplessness, stress • Poor self-efficacy • Work pressures (e.g. difficultly fulfilling job demands) • Problematic social support (e.g. family and friends giving upsetting/unhelpful advice, lack of understanding)	• Noise • Poor lighting • Temperature extremes • Uncomfortable furniture • Inefficient equipment positioning, work heights, or room layout • Transport issues (e.g. long commutes)

Fatigue management strategies:

A) Energy conservation

B) Sleep Hygiene

C) Cognitive Interventions

D) Physical Interventions

E) Medical Interventions

(Dziedzic and Hammond 2010)

A) **Energy Conservation**

This aims to reduce fatigue, pain and increase activity tolerance to achieve overall greater productivity and quality of life without exacerbating pain.

In Farren *et al* (2013) many of the AS participants interviewed reported coping with fatigue using pacing techniques, prioritizing activities, budgeting energy and resting during the day. Hammond (2010) recommends similar practical strategies for energy conservation including:

Pacing: Regular short breaks e.g. 3-5 minutes every 30-45 minutes sitting and relaxing joints or microbreaks e.g. 30 seconds every 5-10 minutes stretching and relaxing those joints and muscles being most used can be very useful and can improve duration of physical activity.

Balancing activities: Patients can balance activities by alternating heavy, medium and light activities during the day and throughout the week. It is important to avoid the 'boom and bust cycle' where many patients do too much on 'good days' and have to endure the consequences several days later.

Positioning: Patients should maintain efficient posture during activities. Supportive seating and ergonomic devices such as bookstands can assist in this. Prolonged sitting and standing should be avoided by changing position regularly or taking a short stretch.

Planning: Planning includes work simplification strategies such as organising tasks more efficiently, carrying out tasks with different equipment or delegating tasks to someone else.

(Hammond 2010)

B) Sleep Hygiene

Sleep diaries can be helpful as they can help identify reasons for poor sleep quality. Other solutions to poor sleeping habits can include more supportive mattresses and pillows; establishing a regular bedtime routine; avoiding stimulants 2-3 hours before bedtime; reducing stimuli in the bedroom e.g. computers and televisions; and having a muted relaxing colour scheme in the bedroom (Hammond 2010). The NICE chronic fatigue guideline backs up the use of education about sleep hygiene and also recommends the discouragement of excessive daytime sleeps (National Institute for Health and Clinical Excellence 2007).

C) Cognitive Interventions

Potential psychosocial causes of fatigue should be evaluated. These include loss of valued activities, poor self-efficacy, anxiety, and problematic social support. Cognitive approaches that can be used include stress management; mindfulness therapy; goal setting to increase activity engagement; assertiveness and communication training; liaising with family and carers (Hammond 2010).

D) Physical Interventions

Regular physical activity and exercise reduce aches, pain and fatigue and improves sleep quality. Current levels of physical activity should be evaluated and any barriers to exercise should be addressed (Hammond 2010).

E) Medical Interventions

Pollard et al (2006) found that good pain control can significantly reduce fatigue. Patients should be encouraged to take analgesia and prescribed medication effectively (Hammond 2010). Anti-TNF-a agents have also been shown to be efficacious at reducing fatigue in most patients (Braun *et al* 2002, Calin *et al* 2004, Gorman *et al* 2002 and van der Heijde *et al* 2005 cited in Farren *et al* 2013). In some cases amitriptyline may be prescribed for restoration of sleep patterns.

Measurement of fatigue

As fatigue is a major symptom of AS, valid and reliable measurements tools are essential to monitor progression and severity. The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI) and Bath Ankylosing Spondylitis Functional Index (BASFI) test have been shown to be reliable and valid in measuring fatigue in AS (Haywood *et al* 2005).

3.2 Flares

What is a 'flare'?

'Flare' is a term used to describe a period of increased disease activity in rheumatic conditions such as AS (Brophy and Calin 2002). A flare is typically followed by a temporary period of remission where symptoms subside or sometimes disappear completely (Spondylitis Association of America (SAA) 2012). In study involving a cohort of AS patients with radiologically proven involvement of the sacroiliac joints, up to 70% of participants reported experiencing a flare in any given week (Cooksey *et al* 2010). These subjectively reported flares were shown to correlate with a validated measure of disease activity, the BASDAI. Scores for the BASFI and VAS night pain scores were also shown to rise significantly during flares with these increases being clinically relevant (Cooksey *et al* 2010).

Types of flares:

There appears to be two patterns of flares in AS:

1. Localized (minor) flares:

    Involve acute pain (above normal levels) and immobility affecting one area e.g. the neck, knee, ankle or back (Brophy and Calin 2002) with minimal systemic symptoms such as fatigue or stiffness (Cooksey *et al* 2010).

2. Generalised (major) flares:

    Are typically far more severe and involve the whole body (Brophy and Calin 2002). Patients report severe pain and immobility, aswell as symptoms of systemic involvement e.g. fevers, sweating, flu-type symptoms, fatigue. Feelings of depression, anger and withdrawal may also accompany major flares (Cooksey *et al* 2010).

Age, sex, age at disease onset and disease duration do not appear to be any different in those who report major flares and those who only have minor flares (Cooksey *et al* 2010).

How long do flares last?

Duration of flares can vary from days to weeks. In Cooksey et al (2010) study of AS patients, those who experienced major flares reported a gradual build-up of the exacerbation that lasted on average 2.4 weeks.

Do flares affect overall course of disease?

Those who do have a major flare period often tend to have a higher disease activity, higher levels of night pain and worse functional scores during 'flare-free' periods when compared to those who have not experienced major/generalised flares. Thus it is postulated that patients who do experience major flares already have a more severe disease or are at risk for developing worse disease in the future (Cooksey *et al* 2010).

Management of flares:

There are no clear guidelines for the management of flares in AS. The following points have been garnered from the literature and online support group resources which may be of benefit in working with AS patients.

❖ *Medication:* Additional pain relief may be required in times of flares. Patients can to consult their GP/rheumatologist re: medication modification in times of flares.

❖ *Exercise*: Patients can continue gentle stretching exercises to prevent loss of range and maintain mobility. They may need to avoid higher-impact exercise depending on their particular flare. There is currently no evidence on the types of exercise which are most suitable during flares therefore as always prescribe exercise based on your own clinical judgement and patient's individual presentation.

❖ *Pacing/Fatigue management strategies*: During a flare patients may have changed energy levels and may need to modify daily activity to allow for recovery. Advice to patients may include:

• Adjust pacing of activities & take frequent breaks between activities if necessary. Avoid/scale back on activities that increase pain. Ask for help.

• Advice on stress management may also be given due to the impact of stress on fatigue and pain levels.

❖ *Practical Measures* patients may find helpful include: hot bath/shower, heat packs, cold packs, gentle stretches.

(NASS 2012; Arthritis Research UK 2012)

3.3 Joint Protection (JP)

Evidence available is largely relating to RA, however knowledge is transferable to other rheumatological conditions (including AS).

JP is a self-management strategy which is often employed by patients with varying rheumatological conditions. JP methods can be taught be different rheumatological health professionals. The use of assistive devices and pacing techniques are primary methods involved (Hammond & Freeman 2004). JP will assist in the reduction of pain, inflammation and applied stresses to the joints during a person's activities of daily living (ADL) (Cordery *et al* 1998).

JP is an active coping strategy which has stemmed from advancing comprehension of the pathophysiology of joint diseases, biomechanics and the contribution of forces applied to the joints. The objective of JP techniques is to preserve functional ability through modification of movement patterns and methods of activity of joints involved.

Aims of JP in inflammatory arthritis are:
- Reduction of pain both during activity and at rest.
- Lessen forces on the joints, both internal (i.e. muscular compression e.g. strong grip) and external (i.e. forces applied to joints during activities such as carrying) forces should be considered.
- Maintain joint integrity and reduce the risk of development and/or progression of deformity.
- Fatigue management.
- Preserve functional ability.

Joint Protection Principles
- Respect pain: take note of pain as a marker to alter activities.
- Disperse load over numerous joints.
- Use assistive devices and a reduction in weight of objects to change working methods and consequently reduce the force and effort necessary for the completion of tasks.
- Use the joints in their most stable positions.
- Avoid positions of deformity and forces in the direction of the deformity.

- Avoid maintaining the same position for long periods of time.

- For completion of tasks, ensure use of the strongest and largest joint available.

- Do not grip very strongly.

- Employ appropriate body posture.

- Utilise correct moving and handling techniques.

- Maintain muscle strength and ROM. (Dziedzic and Hammond 2010)

Joint Protection Strategies

JP is the application of ergonomics to ADL, work and leisure. Education regarding JP should adopt a systematic approach to alter habits, achieve new solutions and speed up this change. JP strategies include:

1. **Respecting pain:** use as cue to alter activities
2. **Altering working methods:** modify movement patterns during activities to achieve more appropriate positioning e.g. sitting on a perch stool whilst ironing.
3. **Restructuring activities:** improve task completion efficiency by eradicating avoidable steps.
4. **Using assistive devices:** reduce the effort required to complete the tasks e.g. walking devices, jar openers.
5. **Altering the environment:** change set-up so that objects required are more accessible e.g. changing the height of work areas.
6. **Selecting appropriate product designs:** use labour saving equipment (e.g. tumble dryers), use electric rather than manual appliances (e.g. can openers) etc.

Evidence-Based Practice:

Combination of anti-TNF therapy and OT (joint protection and energy conservation): benefits found for pain, function and disability with an increase in use of the self-management techniques related to JP and energy conservation in AS (Spadaro *et al* 2008)

***Evidence-Based Practice:**

Usual Joint Protection Education

- Improvement noted in JP knowledge (1 hour individual education) (Barry *et al* 1994).

- Improved JP knowledge but no improvement in behaviour (2.5 hour education session as part of an 8 hour standard arthritis programme) (Hammond and Freeman 2001, Hammond and Lincoln 1999).

- Interviews showed that only one quarter of patients believed they had made changes (Hammond and Lincoln 1999)

Behavioural Joint Protection Education

- Significant improvement in use of JP techniques, improved functional ability and improved pain and stiffness (8 hour CBT JP programme with a 2.5 hour standard arthritis programme) (Hammond and Freeman 2001).

- These benefits were still present at a follow-up of four years and the patients also had fewer hand deformities (Hammond 2004)

Combined Joint Protection, Fatigue Management and Exercise

- Significant improvements in pain, functional status, physical ability, self-efficacy and psychological status in those with established RA (Hammond *et al* 2008, Masiero *et al* 2007).

- Significant improvements in grip strength and patient perceived hand function at three months in an OA population (Stamm *et al* 2002).

(Dziedzic and Hammond 2010)

3.4 <u>Patient Compliance</u>

Physiotherapists may only interact with patients for two or three review sessions in the year therefore it is of vital importance that patients take responsibility for their own home exercise programmes outside of supervision and are compliant with same.

Current literature suggests there is a large discrepancy between the recommendations for exercise participation in AS and the actual reality of AS patients participating in exercise (Lim *et al* 2005; Passalent *et al* 2010). Data on exact compliance rates in AS is lacking however with many of the exercise trials failing to monitor exercise adherence (Dagfinrud *et al* 2011).

To encourage adherence it is important to be aware of the potential barriers to exercise participation. Knowing the reasons why patients are not complying with exercise can help in developing strategies to improve adherence.

Barriers to Exercise:

A survey carried out by Sundstrom *et al* (2002) of 194 patients with AS reported 'fatigue' and 'lack of time' as the main barriers to exercise in this population followed by flares, exercise being too tedious, economic factors and distance to exercise facility.

Other reported factors influencing adherence include:

- Patients' find exercise boring/dislike exercise
- denial of the need to exercise
- lack of knowledge of benefits of exercise
- poor body image discouraging exercise
- lack of short-term gains with exercise   (Barlow 2009, p.145)

It is also reported that patient's with lower levels of disability are not as motivated to carry out regular exercise as those with greater levels of disability (Falkenbach 2003).

Exercise Preferences:

The forms of exercise most commonly performed by AS patient include:

1. Walking
2. Pool exercise
3. Cycling
4. Supervised group exercise   (Sundstrom *et al* 2002)

Pool exercise followed by walking were rated as giving greatest perceived symptom relief and as being the most enjoyable to perform (Sundstrom *et al* 2002). This should be taken into account when designing exercise programmes to improve adherence.

Strategies to Increase Adherence:

- ❖ Determine each patient's expectations, attitudes and beliefs towards exercise. Once you are aware of barriers specific to that person they can be worked on.

- ❖ Use goal-setting. Studies have shown that exposure to the "goal forum" approach, with active participation by the patient in the setting of goals, increases patient motivation and leads to better treatment results (Arnetz *et al* 2004).

- ❖ Integrate patients' preferences into the treatment plan (Sundstrom *et al* 2002).

- ❖ Promote a variety of exercises to prevent boredom (Sundstrom *et al* 2002).

- ❖ Use exercise journals to monitor progress (Hidding *et al* 1993).

- ❖ Social support can also encourage motivation to exercise either with a significant other or through group exercise classes (Lorig and Holman 2003).

- ❖ Education: Educate re: the benefits of exercise and the importance of long-term self-management (Lorig and Holman 2003). Educate on how to continue exercise in the face of barriers such as fatigue or flare ups (Sundstrom et al 2002).

3.5 <u>Self-Management</u>

'*Self-management refers to the individual's ability to manage the symptoms, treatment, physical, and psychosocial consequences and life style changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one's condition and to affect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life. Thus a dynamic and continuous process of self-regulation is established'.*

(Barlow *et al* 2002)

Successful self-management of chronic conditions, such as AS, requires sufficient knowledge of the condition and its treatment, performance of condition management activities and application of the necessary skills to maintain adequate psychosocial functioning (Clark et al, 1991). The five self-management skills that form the core of self- management programs are:

1. ***Problem solving***
2. ***Decision-making***
3. ***Resource utilisation***
4. ***Patient-provider relationships***
5. ***Taking action***

As result:

- Patients need problem solving abilities, decision-making techniques, and confidence in their own self-management ability.
- Partnership is needed between patients and health care professionals. We as health care professionals must provide appropriate medical and therapeutic recommendations to patients and then enable them to learn relevant skills and strategies in a concordant relationship.
- Patients must take responsibility for day-to-day management of their condition (Hammond and Niedermann, 2010).

Empowerment

Empowerment is an important concept in the context of self-management. It is the precondition for and the consequence of self-management ability. Empowered patients are able to develop and strength their own competencies e.g., appropriate knowledge, attitudes and skill needed to cope with the disease within their own life (Virtanen *et al* 2007). This is an important construct for patients with chronic rheumatological conditions such as AS as they will constantly have to improve their knowledge and skills in relation to their condition to control the variability of their condition.

Self-Efficacy

Self-efficacy perceptions plays an important mediating role in self-management activities, adoptine and maintaining health behaviour changes, and health outcomes. Bandura first introduced the concept of self-efficacy in 1977. Given equal disease severity, some patients are incapacitated by their condition, while others continue to live a full life and take control in the management of their condition. Self-efficacy may explain this discrepancy. It has been defined as:

'Beliefs in one's capabilities to organise and execute the course of action required to produce given attainments'. (Bandura, 1997)

It is thought that self-efficacy beliefs influence the courses of action pursued, the effort expended, perseverance in the face of difficulties, the nature of thought processes (e.g. encouraging or self-depreciating thoughts) and the amount of stress experienced in demanding situations (Barlow, 2002).

Patients need to have self- efficacy to undertake and adhere to the self-management programme optimally and, thus, benefit from self-management.. It has been observed that having a high sense of confidence in a chronically ill person's ability to perform behaviours that will enable them to control their symptoms may be health enhancing in and of itself (Daltroy, 1993). Equally, having low self-efficacy may mediate changes in health-related or disease self-management behaviours, thus worsening health outcomes, especially pain and mental health status (Shifren *et al* 1999).

Low self-efficacy has been associated with:

- Psychological distress

- Poorer physical functioning

- Greater physical impairment

- Increased pain

- Increased fatigue

- Increased depression levels

- Anxious mood

- Decreased acceptance of the condition

(Barlow *et al* 2002, Beckham *et al* 1994)

Self-efficacy may also be fundamental to the individual's willingness to perform desirable behaviours, to avoid undesirable behaviours, to invoke disinhibition of specific behaviours (Stretcher *et al* 1986), and to undertake favourable behaviour changes (Clark and Dodge, 1999). Higher pain self-efficacy levels have been found to be predictive of physical functioning (Dwyer 1997), adaptive coping effors (Jensen *et al* 1991), less disability and depression (Arstein *et a*l 1999) and reduces avoidance behaviours over an extended period (Asgari and Nicholas, 2001).

Physiotherapy Management:

In clinical terms, it is important to note that although self-efficacy perceptions are open to intervention, it is the individual's perceptions or beliefs about his or her true capabilities that can influence the individual's behaviour. To achieve optimal disease management goals, the health education specialist should be prepared to facilitate patients and caregivers in enhancing self-efficacy for disease self-care and management (Marks *et al* 2005). Assessing which patients have low self-efficacy, and identifying those who might be less likely to perform self-management behaviours as a result is likely to prove especially helpful in modifying health behaviours among those with chronic conditions. Because self-efficacy is potentially modifiable and can impact health status, motivation levels and adherence to prescribed regimens, intervention approaches that focus on self-efficacy hold much promise for improving chronic disease outcomes (Marks *et al* 2005).

Approaches to promote self-efficacy

Bandura (1996) and Stretcher *et al* (1986) suggest that the following strategies can be used by clinicians, to promote patient's self-efficacy:

- Identify and reinforce the patient's past and present successes or accomplishments.

- Direct patients to observe successful behaviours and coping mechanisms of others with a similar condition/presentation.

- Provide positive feedback for the patient's efforts or encourage family members/carers to do this.

- Facilitate the patient in adopting new health behaviours by ensuring that patients do not interpret incorrectly how they are feeling.

Mode of Intervention

Self- management programmes can be group-based, an individualised programme, or a combination of both. Group approaches typically comprise between 6 and 12 participants and may be supplemented with written materials and audiotapes. Barlow et al (2002) found that the range of group-based approaches can be summarised as:

- Group

- Group (1 session) and computer package to use at home

- Group and individual counselling from a health professional (e.g. nurse) either in person or by telephone

- Group and individual telephone follow-up

- Group and individual treatment consultation

- Group and manual and audiotapes/ videotapes

- Group and written materials

Barlow et al (2002) found that individual approaches included:

- Book and audiotape given to individual by doctor

- Computer-generated written advice mailed to individuals

- Internet

- Manual

- One to one with health professional

- TV and radio programmes

- Video of group session and work materials

- Workbook and videotape

Note: Further research must be carried out to identify the optimal frequency and duration of a self-management programme, as there appears to be little agreement on these factors across the literature
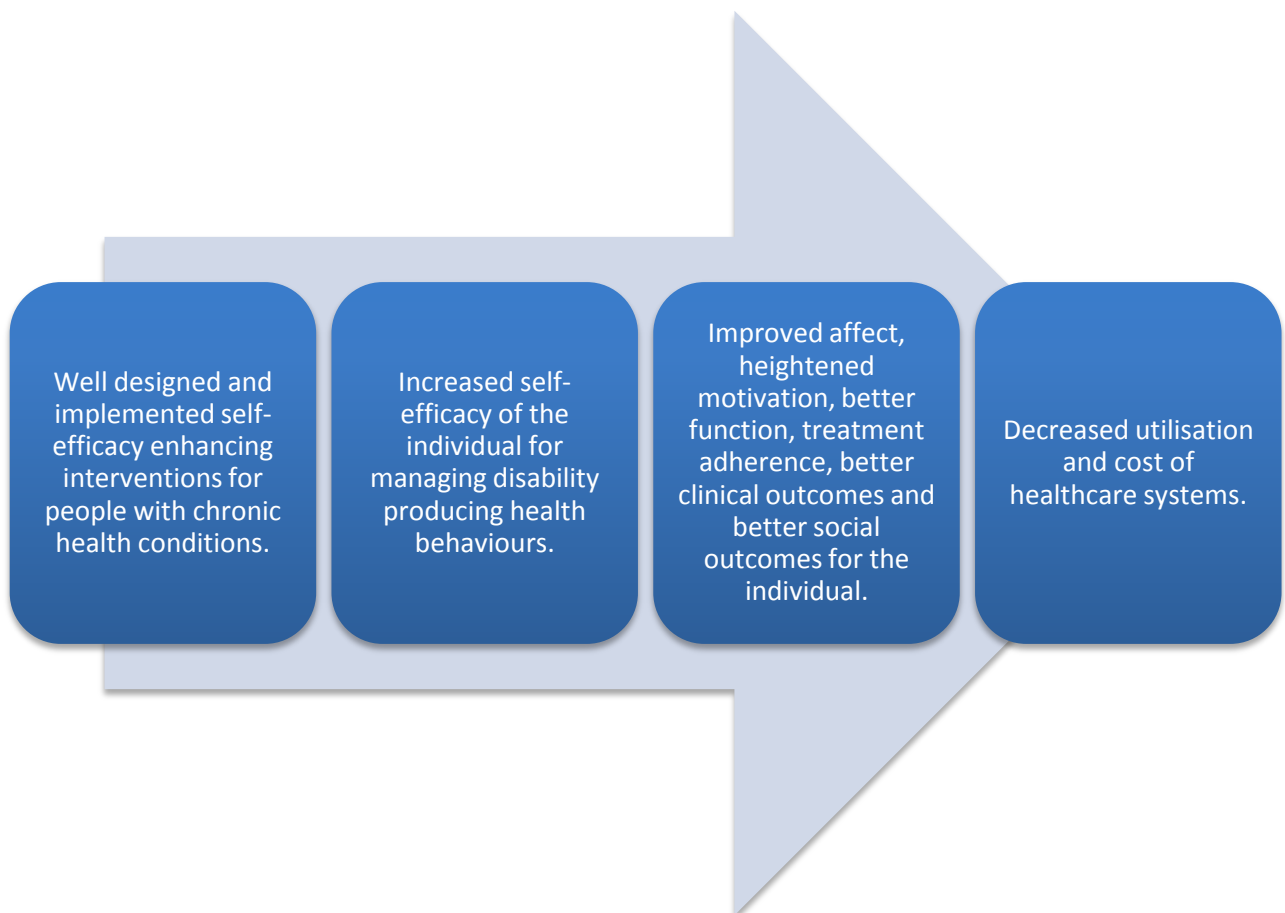
Table 26. Components of Self-Management Programmes (Barlow *et al* 2002)

Main component	Variations and sub-categories
Information	About condition treatment
Drug management	Overcoming barriers to adherence to drugs
Symptom management	Cognitive symptom management Fatigue management Pain management Aggravating factors and warning signs Relaxation Self-monitoring
Management of psychological consequences	Dealing with depression Disease acceptance Emotions Stress management
Lifestyle	Exercise Exercise motivation/overcoming barriers to exercise adherence Leisure activities Smoking, nutrition and diet
Social support	Family support Relationships with peers/family
Communication	Assertiveness Communication strategies (e.g. with health professionals)
Other	Accessing support services Career planning Coping Goal setting Problem solving Spirituality

Effectiveness of self-management programmes

The evidence shows that, when compared to standard care, self-management approaches can provide benefits for participants in terms of knowledge, performance of self-management behaviours, self-efficacy and aspects of health status. (Barlow *et al* 2002). Marks *et al* (2005) created a hypothesised model of effects of self-efficacy enhancing interventions for people with chronic diseases, see below.

Diagram 3. Self-efficacy enhancing interventions for people with chronic diseases (Marks *et al* 2005)

Well designed and implemented self-efficacy enhancing interventions for people with chronic health conditions.

Increased self-efficacy of the individual for managing disability producing health behaviours.

Improved affect, heightened motivation, better function, treatment adherence, better clinical outcomes and better social outcomes for the individual.

Decreased utilisation and cost of healthcare systems.

3.6 Activities of Daily Living

Functional difficulties can be a significant feature of AS. Problems associated with activities of daily living should be identified and solutions sought to compensate for loss of motion and improve functional capacity. A study carried out by Singh and Strand in 2009 investigated if spondyloarthropathies affected physical function and health-related quality of life. This postal survey identified 664 patients with spondyloarthropathies. Results indicated that these patients had significantly more limitations in terms of dressing, transfers, walking and overall mean ADL limitations when compared to age matched controls. Each ADL limitation was 1.3-5.3 times higher in patients with spondyloarthropathies and additionally physical health related quality of life was lower when compared to the control group. Patients with more severe disease activity show greater limitations in ADLs (Reilly *et al* 2010)

Another recent study investigated the effect of socioeconomic difficulties in AS patients (Younes *et al* 2010). 50 patients participated in this study which demonstrated that the disease had a significant impact on activities of daily living. The following were reported as problems in ADL's by patients:

- Grooming affected 38%
- Housework: 76%
- Shopping: 92%
- Sporting activities: 96%
- Socialising: 68%
- Travelling: 80%

Patients have described difficulties in maintaining daily activities and leisure pursuits, changes in mood, personality and self-esteem and stigmatisation which in some situations led to withdrawal from social interactions (Hamilton-West and Quine 2009). Patients described how they had to give up activities such as skiing, hockey, sightseeing, dancing etc.

During an exacerbation there can be a considerable loss of function which can affect the patient's ability to cope with personal care/activities of daily living. Often, when the inflammation eventually subsides, there is an improvement in active range of movement which makes most tasks possible again (Swann 2009).

A study by Dagfinrud et al (2005) interviewed AS patients to describe and measure activity limitations and participation restrictions perceived by the patient in the previous year. The most common difficulties reported were interrupted sleeping, difficulty turning their head during driving, carrying groceries and reduced energy levels for social activities.

Making life easier: Tips for ADLs

There are a number of ways in which a patient's ADLs such as toileting/dressing/washing/self care can be altered to make it easier for these tasks to be completed (Swann 2009):

Table 27. ADLs – Assistive Devices and Alternative Techniques

TASK	ASSISTIVE DEVICE	ALTERNATIVE TECHIQUE OR ADAPTATION
Bending to retrieve items	Long handled reacher	
Managing socks	Sock aid/stocking gutter	Raise foot using stool or place on knee
Managing shoes	Slip-on or Velcro-fastening shoes	Raise foot using stool or place on knee
Slight problems getting in/out of bath	Bath board and seat	Additional handrails
Considerable problems getting in/out of bath	Bathlifter	Shower over bath to avoid the need to manage bath transfers
Standing in shower	Shower stool	Wall-hung shower seat
Rising from toilet	Toilet frame	Toilet rails and/or providing a higher seated toilet
Rising from chairs	Chair blocks	Chair of the right height
Rising from bed	Bed handrails	Bed of the right height with a supportive yet comfortable mattress that maintains spinal alignment
Getting comfortable in bed	Place additional pillows strategically in bed for comfort	
Standing in kitchen and beside washbasin	Perching stool	Breakfast/preparation area in kitchen

It must be noted that a lot of patients do not like to use assistive devices as their presence can be deemed unsightly and it can also reinforce their disability (Swann 2009)

Tips on Travelling for the AS patient (Swann 2009)

There are a number of tips you can give your patient before they go:

- Prior to departure see your rheumatologist to make sure everything is ok. Some patients may go for a quick joint injection if they need it.
- Ensure you have enough medication for your trip
- Ensure you double check and take the correct medication
- Always carry your medicine on-board the aircraft and don't check it with your main luggage as this may get lost.
- If you are taking syringes, make sure you get a letter from your rheumatologist stating same and what the medicine is for.
- If your need to refrigerate your medication, you can carry a cooler and ice pack with you. Otherwise you may ask the flight attendant to store your medication temporariliy in an on-board refrigerator (if available).
- If you're flying, ensure to walk around every hour to stretch.
- Ensure you are well hydrated
- It may be a good idea to take travel/health insurance

3.7 <u>Driving</u>:

This has often been reported as a difficulty among AS patients (Wordsworth and Mowat 1986). Holden et al (2004) investigated the effect of driving in AS patients. 84% of patients in this study were dependent on driving for their mobility. 50% of patients reported neck pain as the primary cause for difficulty with driving. 42% of patients reported avoiding certain routes, 17% depended on a passenger for manoeuvres and 11% reported not wearing a seatbelt. There had been one accident reported with 2 near-misses as a result of neck pain/stiffness.

Some driving tips for AS patients are: (Driver and Vehicle Licensing Authority)

- Always wear your seatbelt
- Adjust seat/mirrors as necessary each time you get into the car.
- Avoid driving when you are tired
- If going on a long journey- consider breaking it up- get out of the car and stretch to avoid stiffness
- In order to maintain a good posture when sitting, it might be a good idea to place a small cushion behind your back or under your buttocks
- Ask your GP if your medications affect your driving ability
- Join a breakdown and recovery service for peace of mind.

If buying/adapting a car consider:
- A model with power-assisted steering and automatic gears, as these require less effort.
- Extras such as: a supportive headrest; a moulded back rest; a panoramic rear view mirror and blind spot mirrors added to the wing mirrors.
- Having a fixed head restraint versus a headrest.

3.8 Work & Employment

Work is regarded as being therapeutic and essential for both the physiological survival and emotional well-being of people in modern societies (Perrone *et al* 2000). It acts not just as a source of income but as a proviso of a large number of other benefits as illustrated below.
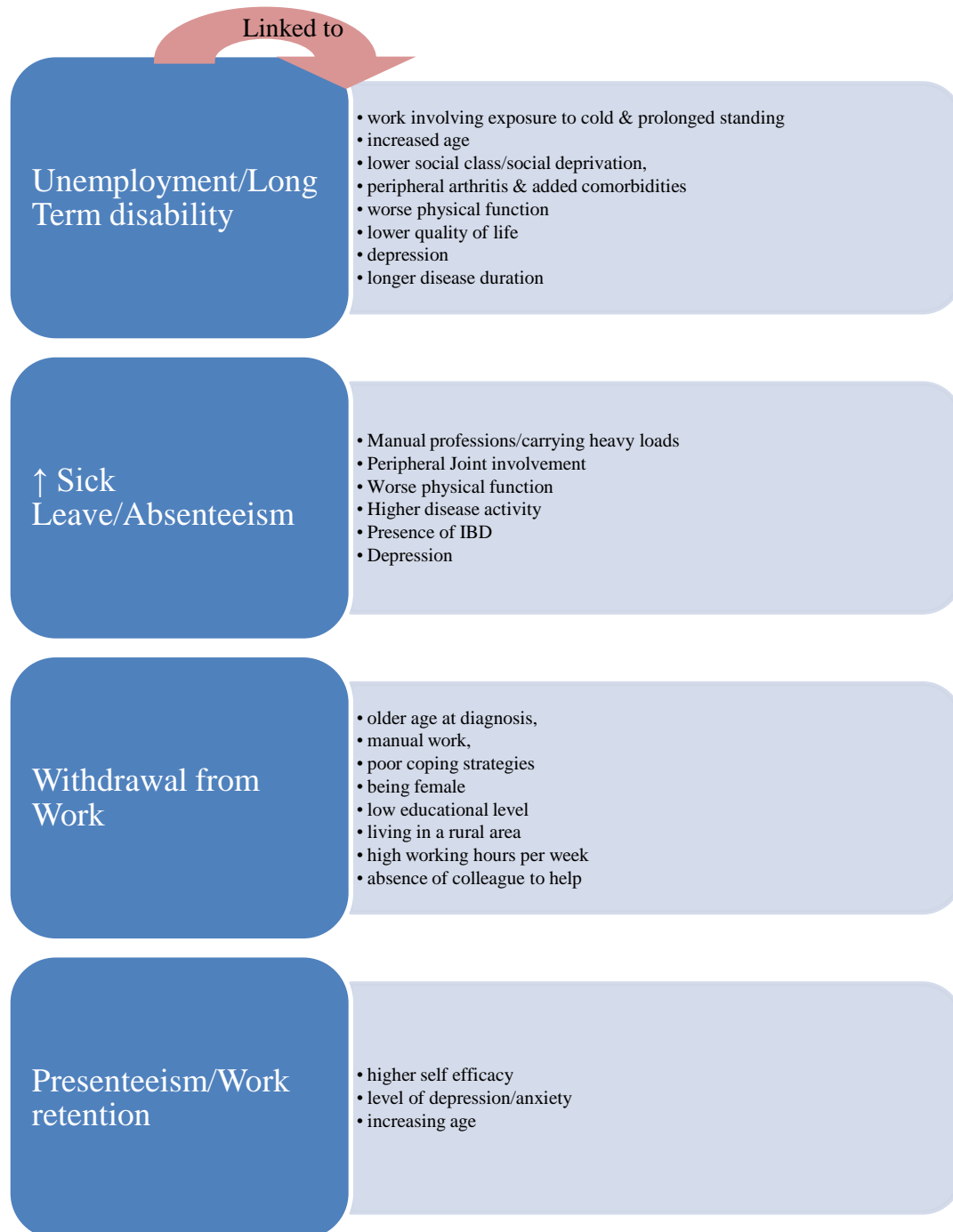
Diagram 4. Employment
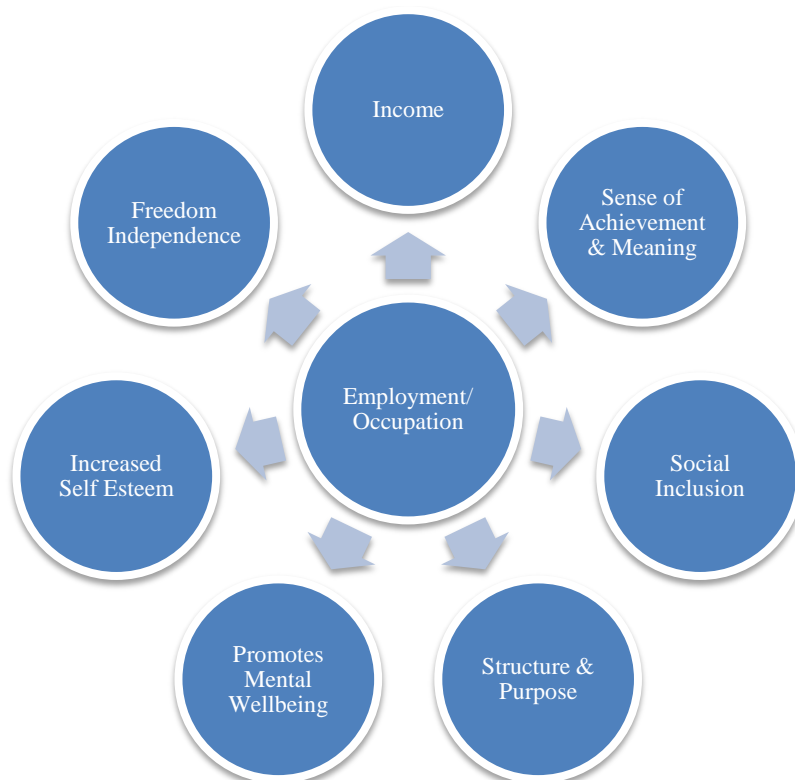
Unfortunately, people with AS are shown to have higher unemployment levels and work disability than the general population especially male AS patients (Healey *et al* 2011; Boonen *et al* 2006). A 2011 study carried out in the UK by Healey *et al* showed that 40% of patients with AS of working age were unemployed.

Of those in work, *5% were shown to have withdrawn from employment during the first year of diagnosis with AS, increasing to more than 20% at 10 years and 30% at 20 years* (Boonen *et al* 2001) with the overall withdrawal rate of AS patients from the workforce estimated to be approximately three times higher than in the general population (Boonen *et al* 2001). Studies have also illustrated that AS patients spent more days on sick leave per year when compared to controls and a greater percentage were registered for sickness/disability benefit (Strombeck *et al* 2009).

This unemployment and work related disability contributes to reduced physical health related QOL in AS and is also an important factor in the total cost and overall economic burden associated with AS (Boonen *et al* 2006; Chorus *et al* 2003).

Factors linked to Work & Employment issues in AS:

Linked to

Unemployment/Long Term disability
- work involving exposure to cold & prolonged standing
- increased age
- lower social class/social deprivation,
- peripheral arthritis & added comorbidities
- worse physical function
- lower quality of life
- depression
- longer disease duration

↑ Sick Leave/Absenteeism
- Manual professions/carrying heavy loads
- Peripheral Joint involvement
- Worse physical function
- Higher disease activity
- Presence of IBD
- Depression

Withdrawal from Work
- older age at diagnosis,
- manual work,
- poor coping strategies
- being female
- low educational level
- living in a rural area
- high working hours per week
- absence of colleague to help

Presenteeism/Work retention
- higher self efficacy
- level of depression/anxiety
- increasing age

(Boonen *et al* 2001; Boonan *et al* 2002; Guillemin *et al* 2005; Healey *et al* 2011; Montacer-Kchir *et al* 2009)

Patient perceived problems at work:

A qualitative study by Lacaille *et al* (2007) investigated the problems and barriers that people with inflammatory arthritis, which included people with AS, experience at work (outlined below). Having a better understanding of these problems can help us as therapists as we work with the patient to devise methods to overcome these problems and facilitate these patients remaining in the workplace. For example, fatigue came out as the number one problem faced by those with inflammatory arthritis. Therefore management strategies as discussed in the fatigue section above could be discussed with the patient.

> *"I find that fatigue brings on guilt. I am not a good employee, why would they keep me hired?"*
>
> Lacaille *et al* (2007) - participant quote

	Problems due to Symptoms & characteristics of the disease	Problems due to Interpersonal difficulties	Problems with Working Conditions	Emotional challenges
Table 28. Summary Of Problems Faced At Work	Fatigue Pain Physical limitation Variability in symptoms Invisibility of arthritis Unpredictable nature of disease & flares Problems with management of disease Patients own strategies to cope with pain &fatigue lead to ↓ potential for job advancement, ↓ job satisfaction and fulfilment	Difficulties with Interpersonal relationships with co-workers Lack of understanding of arthritis by employer/co-workers Fear and reluctance to disclose information about disease	Lack of flexibility Demands of the job Commuting difficulties Working conditions versus need for job fulfilment Difficulty in getting job accommodations Difficulty getting ergonomic modifications	Anxiety, fear & Stress Uncertainty about future Feelings of Inadequacy Guilt Loss of personal fulfilment Depression Frustration at limitations due to arthritis Work & family considerations Financial worries

‣ Employment Equality Act 1998-2011

‣ Equal Status Act 2000 -2011

‣ Equality Act 2004

‣ Disability Act 2005

The legislation above outlaws discrimination in employment. It also states that an:

"employer is obliged to take appropriate measures to enable a person who has a disability to have access to employment, to participate or advance in employment and to undertake training unless the measures would impose a disproportionate burden on the employer."

There are slight variations in the definition of disability in these acts. Generally disability is defined as:

a) the total or partial absence of a person`s bodily or mental functions, including the absence of a part of a person`s body,

b) the presence in the body of organisms causing, or likely to cause, chronic disease or illness,

c) the malfunction, malformation or disfigurement of a part of a person`s body

d) a condition or malfunction which results in a person learning differently from a person without the condition or malfunction,

or

e) a condition, illness or disease which affects a person`s thought processes, perception of reality, emotions or judgement, or which results in disturbed behaviour, and shall be taken to include a disability which exists at present, or which previously existed but no longer exists, or which may exist in the future or which is imputed to a person.

<u>*The Role of the Physiotherapist & Vocational Rehab:*</u>

As being in employment is shown to be a valued life activity it should be assessed regularly by health professionals including physiotherapists. We can perform functional assessments to aid identification of problems at work and can work with the patient and other members of the MDT, such as the OT, to help find solutions (Lacaille *et al* 2007). We can also advise the patient and inform them of resources and supports available to them (Lacaille *et al* 2007).

In terms of vocational rehab programmes De Buck et al (2002) carried out a systematic review on the effectiveness of such programmes for patients with chronic rheumatic diseases. These programmes were aimed specifically at facilitating patients to re-enter or remain in the workforce and were carried out by one or more health professionals. Although the review noted the programmes had some positive effect on vocational status, the evidence of the benefit of these interventions is limited with methodological weaknesses noted in the majority of the included studies.

<u>*Employment Support Services Available to Patients:*</u>

- Trade Unions: If patient has union membership their union representatives at work can offer help and support with workplace issues.
- Citizens Information Board (www.citizensinformation.ie)
- Social welfare (www.welfare.ie)
- FÁS schemes (www.fas.ie)
- Arthritis Ireland (www.arthritisireland.ie)
- Ankylosing Spondylitis Association of Ireland (www.ankylosing-spondylitis.ie/)
- National Ankylosing Spondylitis Society (http://www.nass.co.uk/)

Tips to give Patients:

What can I do?

- **Prioritise your workload** and Plan ahead: What needs to be done and when? If a task is not achievable, can you seek help with it? Or can this task be swapped with a colleague so that you will still contribute.
- Take **regular short breaks** from work: Change position, do some gentle exercises or get up and move around.
- **Change how you work**: Can a more difficult task be done differently? Can the most demanding job be spread out throughout the day or week to prevent discomfort/pain/fatigue?
- **Communicate** with your co-workers: They may be more sympathetic if you discuss it with them so they have a better understanding of your condition.
- Communicate with your employer: Talk to your manager/human-resource contact. **Ask for help** early.

What can my employer do?

- **Talk to your employer**: In order for people to understand your problems you must discuss them. You can then work with your employer to get the most out of your time at work, while looking after your health too.
- Ask your employer for a **workplace assessment**: Simple suggestions or alterations to your work environment could make a big difference! For example a desk of the right height, a more supportive chair, a user-friendly keyboard or other adaptive equipment/technology could help minimise discomfort during work.
- Discuss **altering your role**:
  - Swap specific tasks with other colleagues
  - Agree more flexible working hours
  - Reduce working hours or working from home
- **Review** your situation regularly with your employer as your needs change over time in accordance with your disease.

(Hamilton-West and Quine 2009; NASS 2011; NASS 2012)

3.9 <u>Sexual Activity</u>

Sexual activity is an important dimension of the quality of life of a person (Prins et al 2006). However, sexual activity can be affected by both physical and psychosocial problems (Prins et al 2006). It is these problems that affect sexual activity that can be widely observed in the rheumatology population, peoples with AS, Fibromyalgia and RA.

The literature often examines the presence of sexual dysfunction in these populations. This can be defined as:

> 'the inability to complete the sexual act because of the reduction of sexual drive, orgasm or arousal'   (Pirildar et al 2004).

Other studies may just mention difficulties with sexual activity which may encompass other areas outside the mentioned definition.

Despite sexual difficulties having an effect on a person's quality of life, there is limited research in the area of sexual activity in AS and in other chronic rheumatic conditions such as Fibromyalgia. However, some evidence does exist. Orellana et al in 2008 examined the sexual dysfunction in a range of fibromyalgia patients. All of the participants in this study were women as Fibromyalgia affects predominately the female population (Orellana et al 2008). This study was interesting as it compared Fibromyalgia patients (n=31) to patient's with RA (n=26) as well as a healthy matched control group (n=20).

The main outcome measure for sexual activity used by the study by Orellana et al (2008) was the Changes in Sexual Functioning Questionnaire (CSFQ). The scores for this outcome measure can be observed in the following table:

Table 29. Results of Orellana et al 2008 (CSFQ scores)

	Fibromyalgia	RA	Control
CSFQ (below normal= <41) %	97%	84%	55%
Global Score	2.3 +/- 10.4	27 +/- 10.5	40.7 +/- 11.4
Desire-frequency (normal >6)	4.1 +/- 1.3	4.4 +/- 1.9	7.1 +/- 1.2
Desire-interest (normal >9)	3.9 +/- 1.5	4.5 +/- 1.9	8.1 +/- 3.4
Pleasure- (normal >4)	2.2 +/- 1.1	2.2 +/- 1.1	3.6 +/- .9
Excitation (normal >2)	6.3 +/- 2.7	6.4 +/- 3.1	10.8 +/- 1.4
Orgasm (normal >11)	5.5 +/- 3.7	6.8 +/- 3.9	10.9 +/- 2

As shown the CFSQ score was reduced in RA and FM. The above study also measured levels of depression in the participants, showing that there was a high correlation between high depression scores and sexual dysfunction.

Kalichman (2009) looked in depth at the reasons behind this dysfunction in FM patients illustrating that there were both physiological and psychological factors at play.

Diagram 5. Causes of Sexual Dysfunction in Fibromylagia (Kalichman 2009)
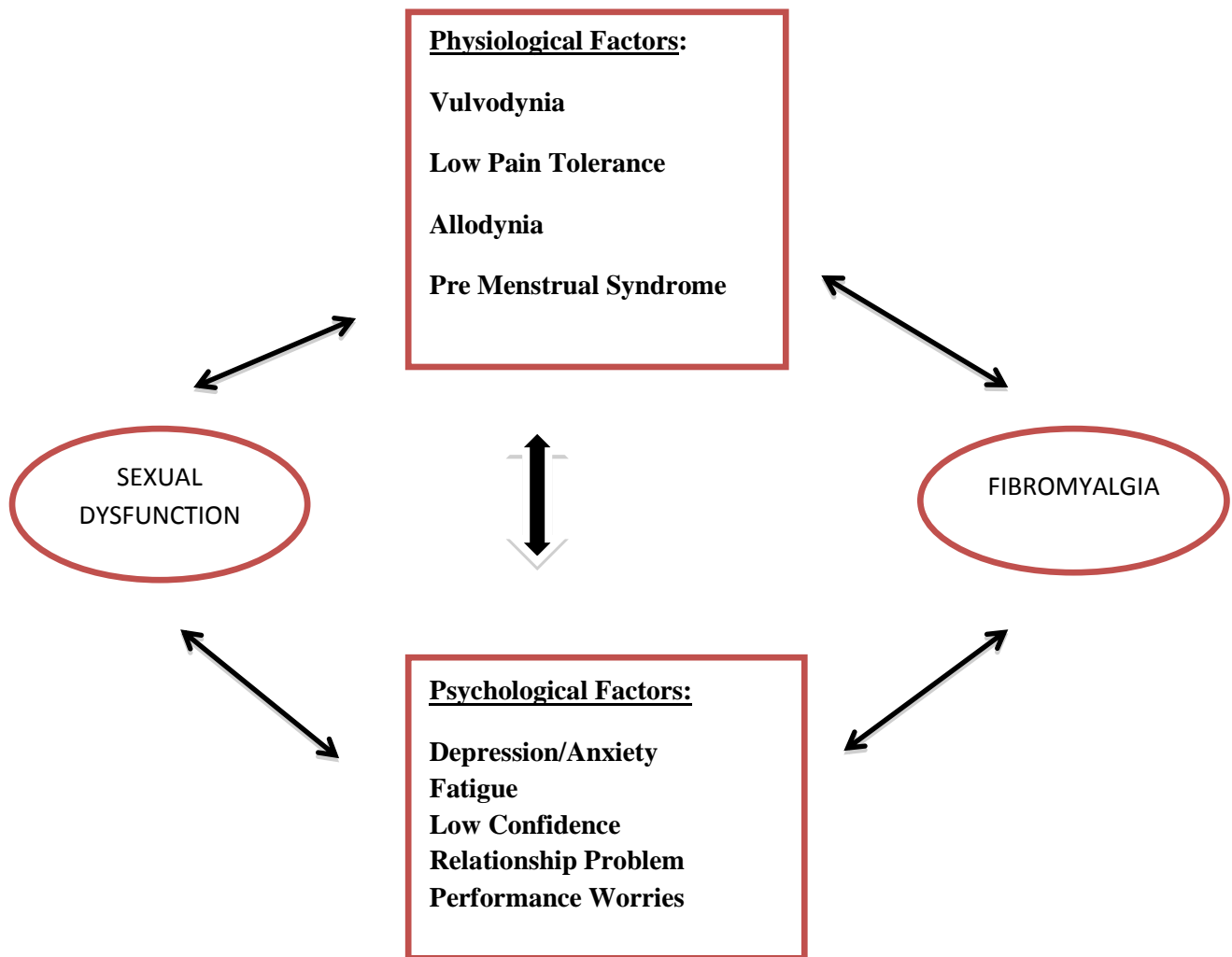
What about AS?

Although both conditions are quite different, similarities are seen between an existence of sexual difficulties in the AS population as well as in the Fibromyalgia population. It is mostly the physical limitations that affect sexual activity for patients with AS but similarly to Fibromyalgia, depression and emotional status are linked to sexual disturbances (Ostensen 2004).

Some studies have also reported no sexual dysfunction in patients with AS, however these studies failed to look at depression and mobility limitation, both of which have been previously correlated with sexual dysfunction in AS (Gallinaro et al 2012).

Sexual dysfunction can greatly affect quality of life as already mentioned and can have detrimental effects on relationships and marriage. This is to be discussed in coming sections.

3.10 Relationships

Marriage:

Marriage encompasses one of the main social roles for an adult and the want/need to take on this role is no different for a person living with a chronic rheumatic disease such as AS, Fibromyalgia or RA (Rowland 1990). Marriage can take the form of a social support and may benefit physical and mental health status in patients with a chronic arthritic disease such as AS and RA (Ward et al 2008).

Patients with AS may find marriage difficult as their physical limitations may lead to intimacy problems as already discussed (Ward et al 2008). One study involving 629 participants with AS investigated the impact that AS may have on marital status and on the likelihood of divorce (Ward et al 2008). Patients in the study were 50% more likely than participants in the general population to have never been married and were 30% more likely to be divorced. This same study concluded that having a chronic disease can affect a patient's mood and social interactions, which may in turn, affect relationships (sexual activity) and cause financial burden. However, globally evidence is limited in understanding why those not married or who are divorced are so.

Impact on Spouses/Partners

The literature also suggests that within the AS population, spouses of patients are at a greater chance of a reduced quality of life and have a higher frequency of depression (Uludag et al 2012). Within these findings, female partners of male AS patients were found to be more effected (Uludag et al 2012).

Partners or spouses naturally take on the role of caregiver in chronic diseases such as AS and Fibromyalgia. A partner has an important influence on the life of a patient with a chronic disease with this influence described by a process called the feedback loop (Keers et al 2003).

The disability experienced by the patient can be correlated with the burden felt by the partner/caregiver (Reich et al 2006). This can force the spouse to be both over protective, discouraging of activity and supportive, thus creating a feedback loop (Reich et al 2006). Higher levels of disability have been correlated with increased support from partners (Reich et al 2006). This is not the natural picture of marriage and marital role and thus creates the feelings and problems discussed above, in terms of depression and decreased sexual activity.

3.11 Parenting

An altered participation role in parenting widely exists among patients suffering with chronic rheumatologic conditions such as AS and Fibromyalgia.

The percentage of people with AS and RA reporting difficulties with parenting are as high as 77% and 97% respectively (Grant et al 2006). Problems that emerged within these reported figures were similar across AS and RA (Grant et al 2006). These problems were lifting a child, encouraging a child and keeping up with a child in terms of energy requirements (Grant et al 2006).

Mother's in particular have been more widely researched in terms of the effect of chronic illness on parenting and for these women, fatigue and physical limitations proved to be the major issues (Thorne 1990). Fatigue was described as a never ending battle and one that lacks a lot of support from health care professionals despite its harrowing effects on both a mother's psychosocial state and that of their child (Grant et al 2006).

Overall participation in mothering tasks can be summed up as 'Sometimes I can, Sometimes I can't' (Backman et al 2007). The study by Beckman et al discusses varying forms of support a mother can avail of once she is participating in her role as a mother (2007). Support systems that can exist are as follows:

- Effective Practical Support- e.g help from a neighbour.
- Absence of Practical Support- e.g can't help share child minding with neighbours for support.
- Emotional Support- from spouse or friend
- A need from support from other parents
- Support from health professionals.

Following either ineffective or effective support a mother/father may determine the effect of their condition on their parenting as beneficial or problematic:

e.g <u>Benefical</u>: '"In an odd way, it's not so bad, because when I cannot move so much, or don't go out, it's kind of bringing the family together. 'Cause then everybody . . . brings our stuff, our projects, our books, and we can talk. The TV isn't on, so that's actually time when I'm available to listen and nothing is rushing me . . . I'm there, mentally I'm there and physically I cannot, but actually, it's not bad, we use that time wisely."

e.g Problematic: "I can't walk to the corner store to get a popsicle or any, you know, any normal thing a parent would do. Bicycling—no, ice skating—no, soccer—no, rollerblading—no, skiing—no. There are no real games or playtime that I can do with them . . . so I think it's sad for them, they're missing out on a lot . . . it affects the family in a lot of areas."

Finally a parent needs to learn to balance energy and fatigue levels, however this may not be manageable at the best of times (Backman et al 2007).

This ideal of parenting can be viewed in the diagram below:

Diagram 6. Parenting
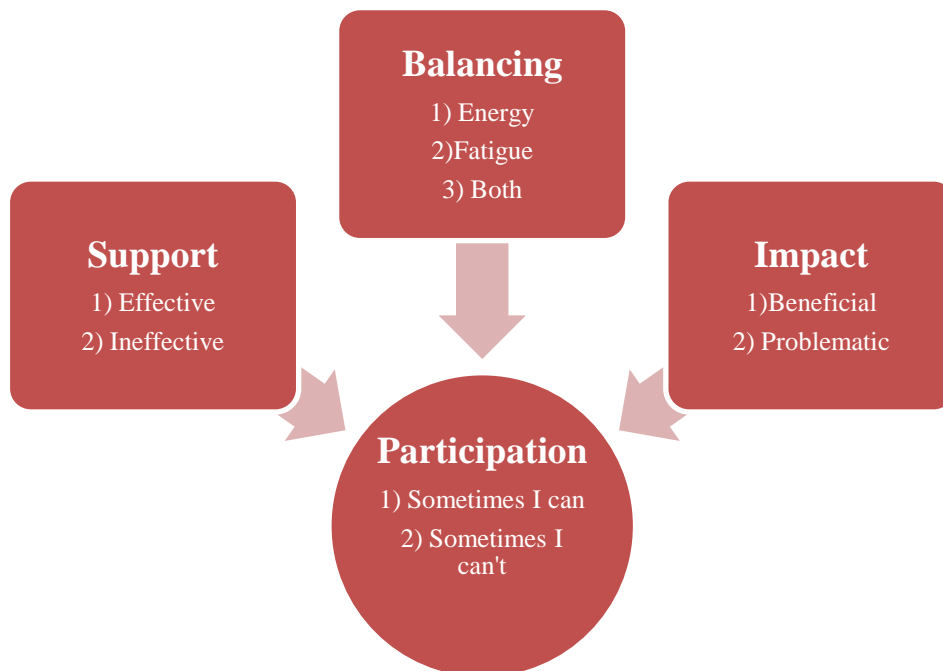
What about the father?

Overall literature is limited for the role of a father with chronic disease, however it appears a father's role is affected more as a child grows older. Difficulties with leisure time are more apparent in later years for fathers.

As already noted, it appears this is an area that needs to be highlighted for further support for patients/parent (Grant et al 2006).

Gender Issues

Study results published by Lee 2007, revealed that damage evident on x-ray is significantly worse among men with ankylosing spondylitis than women even with similar disease duration. Functional disability is not different between men and women with AS, however women tend to "self-report" worse functional disability than men at any stage of disease. Women have a slightly earlier age of disease onset and more frequently reported family history of AS in first-degree family members. These contrasting symptoms often results in varying treatment methods between genders.

(Lee *et al* 2007)

3.12 <u>Self-Esteem</u>

Perceptions and evaluations of one's own body are important sources of self-esteem. Having a rheumatic disease challenges maintenance of positive self-esteem due to consequences of the disease such as unfavourable sensations as pain and limited physical functioning (Bode et al 2010). Low self-esteem can sometimes double the risk of later depression (Brown et al 1990. In a qualitative study by West and Quine (2009), 11 subjects reported low self-esteem and lack of confidence as one of the top negative aspects of living with AS. Body image is also often a common issue that greatly affects self-esteem of AS patients. Gunther et al (2010) found that AS patients (n=56) reported significantly more worries about possible physical deficits, and considered themselves as being less attractive than healthy controls (n=48). Maintaining positive self-esteem is therefore one of the major challenges patients with a chronic disease are confronted with.

3.13 Depression

A UK study by Healy et al (2008) reported that 22% and 13.5% of the 556 AS patients included scored ≥ 11 on the HAD scale indicating levels of definite anxiety and depression respectively. Also Barlow et al (1993) found that about one-third of AS patients reported symptoms of depression. Awareness of these factors should enable health practitioners to focus the early treatment and management of AS more appropriately.

Diagram 7. Depression and Negative Emotions

Depression and negative emotions in rheumatologic conditions can lead to poor patient outcomes via several pathways if not managed correctly.
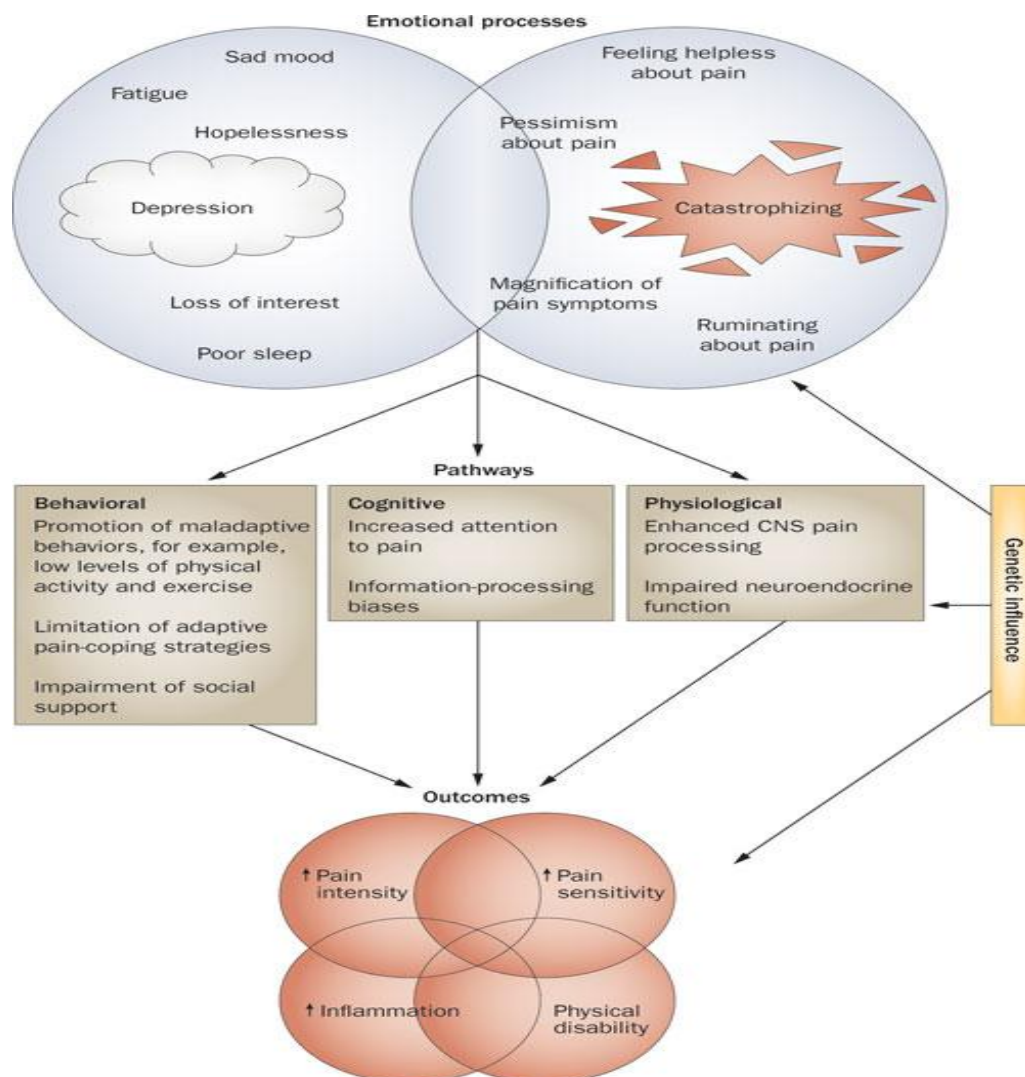
3.14 Impact of Diagnosis (RA)

No evidence available in relation to AS. Evidence available is only related to RA, however knowledge is transferable to other rheumatological conditions (including AS).

Individuals vary greatly in their psychosocial acceptance of the diagnosis of RA, and poor adjustment to this diagnosis contributes to the onset of depressive symptoms. It is recognised that rates of depression may be at least as high for patients recently diagnosed as for those with chronic RA (Sharp et al 2001). Groarke et al (2004) found that illness perception had a greater effect than disease activity on the variance of pain in RA. They found that patients who perceived that the disease would last indefinitely, have serious consequences, with little chance of cure or control, adjusted less well both physically and psychologically. Along with the recognition of the need to treat the physical aspects of the disease early, the concept of a psychological 'window of opportunity' also exists. It is during this time that positive attitudes can be fostered and negative coping mechanisms challenged, with benefits for long-term psychological health.

In everyday practice, there should be an emphasis on providing good psychological support to those with newly diagnosed RA. In addition to information and education about RA, this includes reassurance about the efficacy of modern therapy and engendering a positive attitude. Physiotherapists have a particular responsibility here, as managing this period of adjustment may well have long-term benefits on coping mechanisms and reduce the risk of future depression.

Stages of Grief

The five stages of grief were first hypothesised by the late Elizabeth Kubler-Ross in her 1969 book *On Death and Dying*. The five stages of loss provide an outline for a person to cope with the loss of a loved one. The five stages are:

1. Denial
2. Anger
3. Bargaining
4. Depression
5. Acceptance   (Bolden 2007)

People who receive the diagnosis of any chronic illness may find the emotional adjustment to their diagnosis and the acceptance of same more disabling than the actual condition initially. This may persist until the person accepts their diagnosis and is able to adjust accordingly and embrace themselves as the person with such a diagnosis. In order for this acceptance to be gained, a person may go through some or all of the five stages of grief (Lewis 1998).

Models of Adjustment to Chronic Illness

There are three primary paradigms used to systematise the main components of adjustment to a chronic illness:

1. The Biomedical Model
2. The Psychological Model
3. The Biopsychosocial Models

These models attempt to clarify the way in which people may adjust to the diagnosis of a chronic illness.

The Biomedical Models of Adjustment to Chronic Illness

This model concentrates on disease and disability, what causes the disease and what preventative measure and treatments are available. This model implies a direct correlation between pathophysiology, disease progression and subsequent disability. However, this view is contradicted in the research where the relationship is not viewed as being so simple and that psychosocial and environmental factors must be considered. Despite critique this paradigm has been extremely efficacious in augmenting comprehension of the aetiology, disease course and treatments of a range of health conditions (Larson 1999).

Psychological Models of Adaptation to Illness

Involvement of psychological influences on the course of rheumatic diseases has only been accepted in the past five/six decades (Arnott 1954). Psychological adjustment is now thought to play an important role in illness progression and disease course in chronic illness.

Cognitive adaptation to Illness Models

The cognitive adaptation model to chronic illness proposed by Taylor (1983) focuses on three aspects: the search for meaning, gaining a sense of control over the disease and the restoration of self-esteem.

The Stress and Coping Paradigm as an explanation of Chronic Illness

The manner in which a person with a rheumatological condition copes with their illness has been linked to more positive psychological adjustment outcomes (Smith *et al* 1997).

The Role of Stable Characteristics in Adjustment to Illness

Optimism has ben shown to be an important psychological factor in the adjustment to chronic illness, including rheumatological conditions. It is associated with increased well-being, improved psychological adjustment and decreased stress (Folkman and Greer 2000).

Models of adjustment to chronic illness
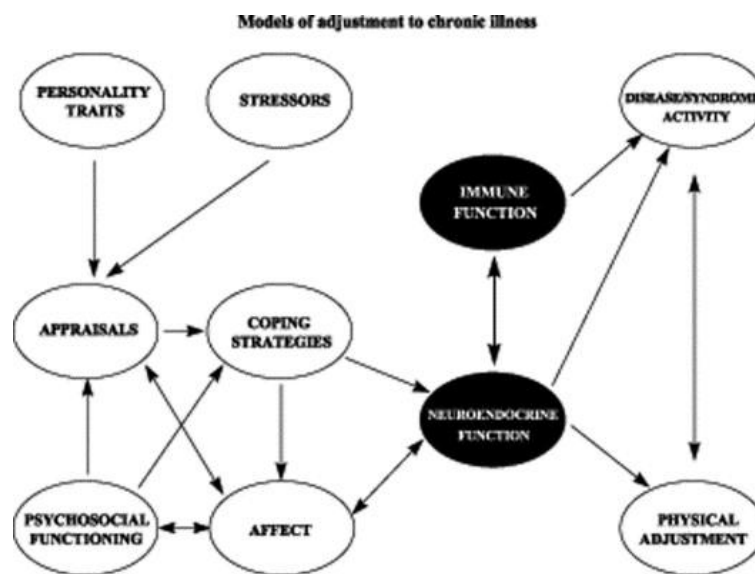
A psychosocial model of adjustment to rheumatic conditions influenced by research into cognitive adaptation and negative affectivity, as well as the stress and coping paradigm. Stressors and predisposing factors, such as personality traits, impact on disease/syndrome activity and physical adjustment outcomes via interactions between psychosocial functioning, cognitive appraisal, coping strategies, and affect.

The Biopsychosocial Framework of Adaptation to Illness

There is increasing amounts of literature suggesting the involvement of psychosocial factors in disease activity and related physical variables e.g. pain and disability. These relationships are complex and not as of yet fully understood in relation to many chronic conditions.

(Walker *et al* 2004)

3.15 <u>Service Provision – AS & FM</u>

Support Groups

1. **Arthritis Ireland** (www.arthritisireland.ie)

   Arthritis Ireland strongly supports the idea of living your life in such a way that it will aid the control of a person's condition. Arthritis Ireland provides a wide range of services, events and programmes which aim to optimise a person's quality of life and enhance the control of their condition. Some programmes they have underway are:

   - 10 steps to easier living
   - Walking groups
   - Living well with arthritis/ Living with Fibromyalgia
   - Fit for work
   - Breaking the pain cycle

   They also provide useful information on how to take control and self-manage ones condition, how to care for someone with a rheumatological condition and how to get involved in programmes such as walking groups in your particular area.

2. **The Ankylosing Spondylitis Association of Ireland (ASAI)** (www.ankylosing-spondylitis.ie)

   The mission of the ASAI is to enhance the awareness of AS in the general public, for patients and for medical professionals and also to highlight its effects and management. It also provides support and advice to people seeking this information.

   Services available to its members:
   - Organised hydrotherapy sessions.
   - Regular talks on the condition and its management and provide materials to support patients including hints on living with AS, tips on exercising, exercise DVDs and regular newsletters.
   - iPhone apps specific for AS (not yet available on Android)
   - "Watch Your Back" awareness campaign: Young people in Ireland are experiencing an average delay of seven years before they are diagnosed with Ankylosing Spondylitis (AS). In response, we have launched a nationwide campaign in General Practitioner (GP) surgery waiting rooms across Ireland to

highlight to young people the importance of paying attention to persistent low back pain.

3. **Fibro-Ireland** (www.fibroireland.com)

Fibro-Ireland was created to provide information and understanding to those suffering from fibromyalgia. The organisation aims to listen to patient experiences with empathy, enhance general comprehension of the condition, provide information of FM which is current and provide support to those who are caring for someone with fibromyalgia.

4. **Chronic Ireland – The Irish Chronic Illness Community** (http://www.chronicireland.com/)

Chronic Ireland is an online, non-profit making community website that aims to help people with a chronic condition find support groups in their area, keep people up to date with the current research in their condition and facilitate peer support through their discussion forum and central hub.

5. **The Irish Wheelchair Association (IWA)** (www.iwa.ie)

The IWA is an important provider of services to those with limited mobility. AS patients may fall into this category. The aim of the IWA is to achieve enhanced independence, freedom and choice for those living with a disability.

Services provided by the IWA include:

- Advocacy
- Assisted living services
- Corporate training
- Holidays
- Housing
- Motoring
- Rehabilitative training
- Resource and Outreach
- Sport
- Youth services
- Wheelchair services

Services & Entitlements

There are a number of services and entitlements available to adults with disabilities which are likely to last more than one year. Some benefits are means-tested. One may apply however not everyone will be granted the payments. People with AS or FM are not entitled to a long-term illness card (HSE 2012). Services and entitlements fall under the following headings:

Social Welfare Payments

- Invalidity Pension
- Disability Allowance (means tested)

Extra Payments

- Additional social welfare benefits/Supplementary welfare/Allowance schemes

Transport & Mobility

- Disabled persons parking card
- Mobility allowance
- Motorised transport grant

Working while getting a disability payment

- FÁS training courses/Community employment
- Workplace/equipment adaptation grants

Education & Training

- Rehabilitation and training services

Health Services & Community Supports

- Home help service
- Physiotherapy/Occupational therapy/Public health nurses

Tax Credits

- VAT refunds on aids and appliances used by people with disabilities

Housing

- Housing adaptation grant
- Mobility aids grant scheme
- Applying for local authority housing (Citizens Information 2012)

Services for people with ankylosing spondylitis in the UK: a survey of rheumatologists and patients (Hamilton et al 2011)

- Questionnaires re: experiences surrounding diagnosis, treatment and access to therapies were distributed to 2000 non-health care professionals who were members of the National Ankylosing Spondylitis Society (NASS). 40% response rate.

- Questionnaires regarding services offered to AS patients distributed to a consultant rheumatologist in every acute NHS hospital in the UK. 68% response rate.

- Results: Mean diagnostic delay of 8.57 years
  - o 32.2% of patients were not reviewed in secondary care
  - o 20% of patients on anti-TNF-alpha therapy
  - o 18.8% of departments reported restricted ability to distribute anti-TNF therapy due to primary-care trust rationing (64%) and staff shortages (14%))
  - o Almost all departments had access to MRI. However, 70.9% of departments continued to use x-ray as their first-line investigation.
  - o 5.6% of patients had never attended physiotherapy. <33% of patients had the ability to self-refer for treatment when they were experiencing a flare.

- Conclusion: This is the first study carried out looking at services available to AS patients in the UK. It is possible that nearly 1/3 of patients may be under-treated as a result of not being seen in a rheumatology department. For the remaining patients who are seen, provision of services such as anti-TNF therapy is still an issue.

There has been no such study carried out in Ireland to date.

3.16 **Resources For Physiotherapists And Patients**

Online resources:

- Ankylosing Spondylitis Association of Ireland: www.ankylosing-spondylitis.ie/

- Arthritis Ireland: www.arthritisireland.ie

- Arthritis Research UK- Ankylosing Spondylitis: http://www.arthritisresearchuk.org/arthritis-information/conditions/ankylosing-spondylitis.aspx

- National Ankylosing Spondylitis Society (UK): http://www.nass.co.uk/
  "Back to Action" exercise booklet and phone app: Free information on exercise management of Anyklosing Spondylitis
  http://www.nass.co.uk/exercise/exercise-for-your-as/back-to-action/

3.17 Fibromyalgia Syndrome (FMS)

What is it?

The word `fibromyalgia` comes from the Latin 'fibro' meaning fibrous tissue and the Greek words for muscle "myo" and pain "algia".

It is also known by many other names including:

- chronic rheumatism,

- myalgia,

- muscular rheumatism,

- fibrositis

-myofibrositis.

Fibromylagia syndrome (FMS) is a syndrome of widespread pain, multiple tender points, decreased pain threshold and abnormal pain processing with characteristic symptoms that include sleep disturbances, fatigue, psychological distress aswell as many other less common features. FMS can be extremely debilitating for those with severe symptoms interfering with basic daily activities and reducing QOL (Huynh *et al* 2008).

Prevalence

The prevalence of FMS in the overall population is estimated at approximately 2%, most commonly affecting women aged between 35 to 55 years (Huynh *et al* 2008).

Prevalence rates for CWP and fibromyalgia by age and sex across the adult lifespan.
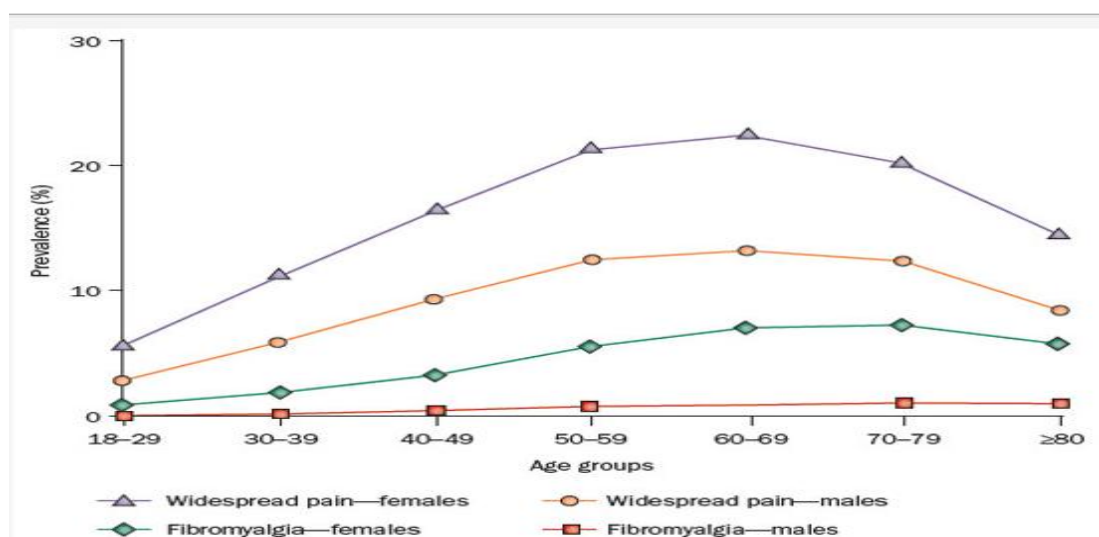
(McBeth and Mulvey 2012)

Aetiology and Pathophysiology

The aetiology and pathophysiology of FMS remains largely unexplained (Abeles *et al* 2007). Research suggests there are multiple overlapping factors contributing to its pathogenesis. These factors include:

1) **Biologic Abnormalities**
2) **Genetic Factors**
3) **Environmental Factors**

1) Biologic Abnormalities in Fibromyalgia

Neuroendocrine System:

FMS involves abnormal functioning in the hypothalamic-pituitary-adrenal axis. Studies have shown that patients with fibromyalgia often have an inability to suppress cortisol, displaying significantly higher overall plasma cortisol (P <0.001) and higher peak and trough levels of plasma cortisol (Crofford *et al* 1994 cited in Bradley 2009). It is unclear if these hormonal and biochemical abnormalities seen in FMS are due to a disease process or are secondary to the pain itself.

Autonomic Nervous System:

Derangement in ANS functioning characterised by increased sympathetic and decreased parasympathetic tone (Cohen *et al* 2000) is often observed in FMS. This derangement may contribute to enhanced pain and other clinical problems by altering the physiologic responses required for effective stress management (e.g. increases in blood pressure) and pain inhibition through diminished production of growth hormone and insulin-like growth factor (Bradley 2009). Difficulty in maintaining blood pressure levels for example may contribute directly to some of symptoms associated with FMS like fatigue and dizziness (Bradley 2009).

Dysfunction in Pain Processing

Pain processing dysfunction is another hypothesis in the aetio-pathogenesis of FMS (Yunus *et al* 1992). This hypothesis suggests that chronic widespread pain is due to abnormalities involving the pain and sensory processing systems of the central nervous system (CNS) (i.e. the spinal cord and brain) (Velkuru *et al* 2009). Many studies have shown an exaggerated response to pain in the CNS of patients with FMS. This is known as central sensitisation (Gracely *et al* 2002).

Sleep Disturbances

FMS patient often have sleep disturbances including insomnia, non-restorative sleep, early morning awakening, and reduced sleep quality in general. This sleep dysfunction may be linked to the reduced energy and fatigue suffered by FMS patients.

In polysomnography studies of FMS patients, alpha-delta sleep patterns which are linked to non-restorative and interrupted sleep were observed frequently (Harding 1998 cited in Bradley 2009). These frequent alpha-wave intrusions during sleep can lead to a reduction in the production of growth hormone and insulin like growth factor (Van Cauter *et al* 1998 and Prinz *et al* 1995 cited in Bradley 2009) leading to impaired healing of muscle tissue damage, thereby prolonging the transmission of sensory stimuli from damaged muscle tissue to the CNS and enhancing the perception of muscle pain (Bennett *et al* 1992 cited in Bradley 2009)

2) Genetic Factors and Family Influence on Fibromyalgia

It appears there is a strong genetic component in FMS. It has been shown that first degree relatives of FMS patients are nearly 9 times more likely to have FMS when compared to relatives of patients with Rheumatoid Arthritis (Arnold *et al* 2004). They also have a greater likelihood of having regional pain syndromes and mood disturbances (Velkuru *et al* 2009).

Candidate Genes

Results from several investigations indicate that specific genetic polymorphisms to genes affecting serotonin and catecholamine metabolic or signalling pathways can contribute to enhanced pain sensitivity, variation in sensory processing and increased risk of developing pain syndromes such as FMS (Bradley 2009). The candidate genes include a single nucleotide polymorphism (SNP) in the serotonin transporter (*5-HTT*) gene and variants in catechol-O-methyltransferase (*COMT*) genes (Bradley 2009).

3) Environmental Triggers

Environmental factors can play an important role in the genesis of FMS. FMS symptoms may be triggered by physical or psychosocial stressors.

Physical Stressors

Physical trauma or injury such as acute illness, physical injury, surgery, and motor vehicle accidents have also been linked to the development of pain syndromes and widespread pain (Bradley 2009). Illnesses involved included certain infections such as hepatitis B and C,

HIV disease, parvovirus, Lyme disease, and Epstein-Barr virus (Abeles *et al* 2007). Other diseases linked to increased chance of developing FMS include hypermobility syndrome and chronic autoimmune conditions like Rheumatoid Arthritis, Systemic Lupus Erythemastosus, and Inflammatory Bowel Disease (Abeles *et al* 2007).

Psychosocial Stressors

Psychosocial stressors which can trigger FMS include chronic stress, workplace dissatisfaction, emotional trauma, and emotional, physical, or sexual abuse. The level of psychosocial stress may also affect the severity of pain & pain sensitivity in FMS (Velkuru *et al* 2009).

Diagnosis:

There is some difficulty in diagnosing FMS due to the absence of a gold standard or case definition. Current diagnostic tools include:

1) **The American College of Rheumatology (ACR) 1990 Criteria for the Classification of Fibromyalgia.**
2) **ACR (2010) Classification for Diagnosis of FMS**

Final diagnosis is based on a combination of a thorough history and physical examination. Laboratory blood tests and some imaging techniques may also be of use both in ruling out other conditions and diagnosing FMS.

1) The American College of Rheumatology (ACR) 1990 Criteria for the Classification of Fibromyalgia.

Diagnosis based on history of widespread pain present for at least three months & Pain in 11 of 18 tender point sites on digital palpation (http://www.nfra.net/Diagnost.htm)

Some issues with ACR (1990) Classification Criteria:

- The criteria are largely subjective.
- It only takes into account pain- not the other aspects of FMS (e.g. insomnia and fatigue).
- The reliability of the examination for tender spots can be influenced by the amount of pressure applied.
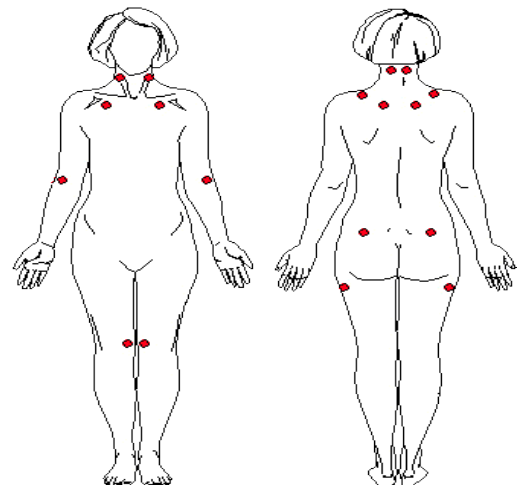
2) **ACR (2010) Classification for Diagnosis of FMS**

This does not require a tender point examination and also provides a severity scale for characteristic FMS symptoms. It involves a combination of the Symptom Severity (SS) scale and Widespread Pain Index (WPI) of

(WPI >7 AND SS >5)

or

(WPI 3–6 AND SS >9)

Figure 3: ACR (2010) Diagnostic Criteria

Criteria

A patient satisfies diagnostic criteria for fibromyalgia if the following 3 conditions are met:
1) Widespread pain index (WPI) ≥7 and symptom severity (SS) scale score ≥5 or WPI 3–6 and SS scale score ≥9.
2) Symptoms have been present at a similar level for at least 3 months.
3) The patient does not have a disorder that would otherwise explain the pain.

Ascertainment

1) WPI: note the number areas in which the patient has had pain over the last week. In how many areas has the patient had pain? Score will be between 0 and 19.

Shoulder girdle, left	Hip (buttock, trochanter), left	Jaw, left	Upper back
Shoulder girdle, right	Hip (buttock, trochanter), right	Jaw, right	Lower back
Upper arm, left	Upper leg, left	Chest	Neck
Upper arm, right	Upper leg, right	Abdomen	
Lower arm, left	Lower leg, left		
Lower arm, right	Lower leg, right		

2) SS scale score:

Fatigue
Waking unrefreshed
Cognitive symptoms

For the each of the 3 symptoms above, indicate the level of severity over the past week using the following scale:

0 = no problem
1 = slight or mild problems, generally mild or intermittent
2 = moderate, considerable problems, often present and/or at a moderate level
3 = severe: pervasive, continuous, life-disturbing problems

Considering somatic symptoms in general, indicate whether the patient has:*

0 = no symptoms
1 = few symptoms
2 = a moderate number of symptoms
3 = a great deal of symptoms

The SS scale score is the sum of the severity of the 3 symptoms (fatigue, waking unrefreshed, cognitive symptoms) plus the extent (severity) of somatic symptoms in general. The final score is between 0 and 12.

Clinical Features:

Symptoms of FMS: (Aaron *et al* 2001)

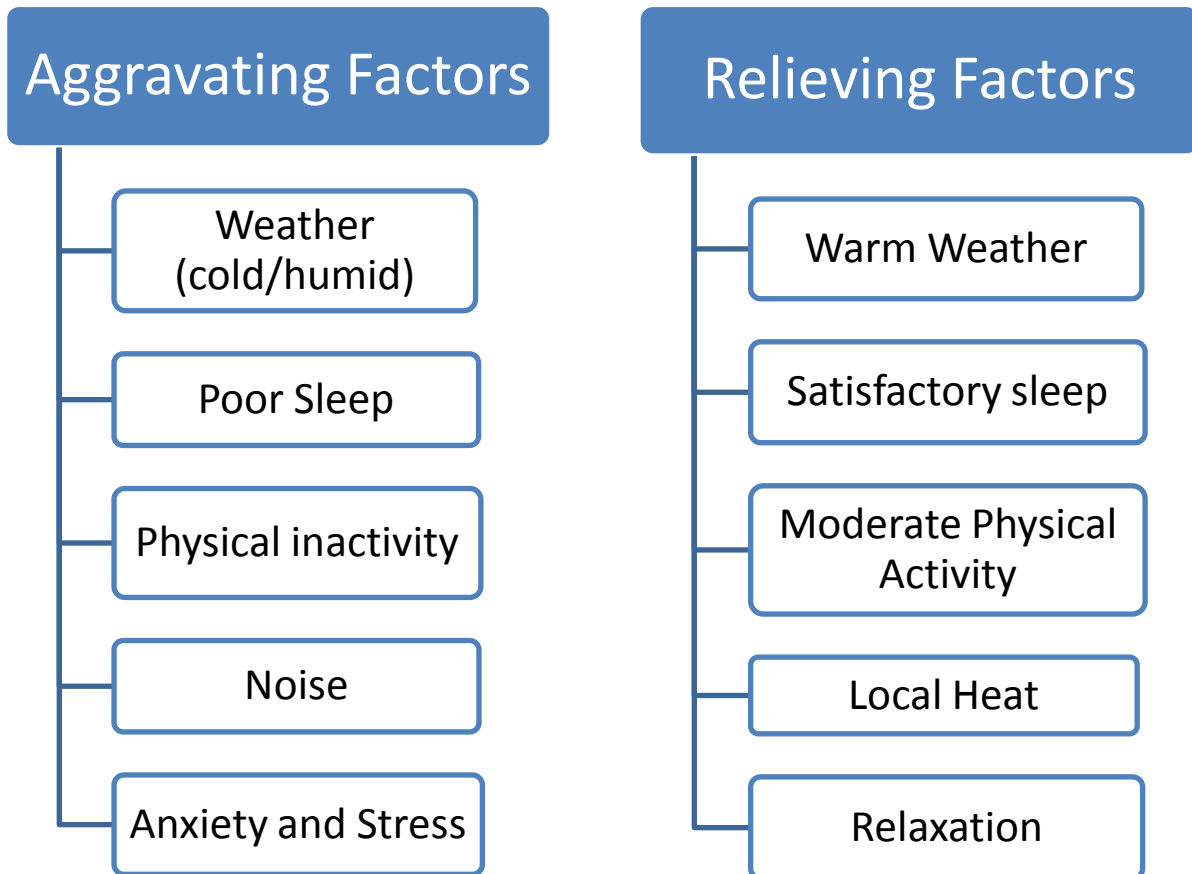| Primary Symptoms of FMS |
|---|
| Diffuse Pain |
| Fatigue |
| Sleep Disturbance/Insomnia/Poor sleeping patterns |
| Depression |
| Anxiety |
| **Secondary Symptoms of FMS** |
| Cognitive dysfunction- 'Fibrofog' |
| Impaired Memory/Concentration |
| Irritable Bowel Syndrome/ Irritable Bladder |
| Headaches |
| Night Sweats |
| Restless Legs, Leg Cramps |
| Vaginal Pain/Vulvodynia/Painful Menstrual Periods |
| Numbness and Tingling |
| Dyspnoea, Palpitations |
| Mood disturbance & Psychological Distress |
| Variety of other physical and psychological symptoms |

The main pain locations in FMS include the neck and shoulders to axial skeleton, the chest wall and the hips with pain in the extremities also occurring. Pain in FMS is described in terms such as:

'Widespread, Gnawing, Migratory, Aching, Exhausting, Burning, Unbearable, and Deep'. (Velkuru *et al* 2009)

The majority of patients with FMS also experience some form of mood disturbance (anxiety, personality change, depression), and cognitive dysfunction (short-term memory loss, impaired concentration) are present in a majority of patients (Yunus 2007).

Reported Aggravating & Relieving Factors in FMS

Aggravating Factors	Relieving Factors
Weather (cold/humid)	Warm Weather
Poor Sleep	Satisfactory sleep
Physical inactivity	Moderate Physical Activity
Noise	Local Heat
Anxiety and Stress	Relaxation

Management of FMS:

'EULAR evidence-based recommendations for the management of fibromyalgia syndrome'

GENERAL CONSIDERATIONS for FMS management:

- A comprehensive evaluation of pain, function & psychosocial context is required to understand FMS as it is a complex, heterogeneous condition (level IV D).
- A multidisciplinary approach including a combination of non-pharmacologic and pharmacologic interventions is required. Treatment should be tailored to each patient based on intensity of pain, function, and associated features including depression, fatigue and sleep difficulties (level IV D).

Recommendation on **NON-PHARMACOLOGICAL** management:

- Heated pool treatment, with or without exercise, is effective (level IIa B).
- For some FMS patients, an individually tailored exercise program can be beneficial. This program may include aerobic exercise and strength training (level IIb C).
- Cognitive behavioural therapy may be beneficial for certain patients with FMS (level IV D).
- Relaxation, rehabilitation, physiotherapy, psychological support, and other modalities may be indicated depending on a patients individual needs (level IIb).

Recommendations on **PHARMACOLOGICAL** management:

- Tramadol is recommended for pain management (level A). Simple analgesics (eg, paracetamol) and other weak opioids may be considered, however corticosteroids and strong opioids are not recommended (level IV D).
- Antidepressants are recommended to reduce pain and improve function (level Ib A). These may include amitriptyline, fluoxetine, duloxetine, milnacipran, moclobemide, and pirlindole.
- Tropisetron, pramipexole, and pregabalin are recommended to reduce pain in

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