

AS Patient

How to Cope with the Lifelong and Changing Disease Challenges



Dieter Wiek

KEYWORDS

- Late diagnosis
- Medication
- Disclosure
- Eye problems
- Physiotherapy
- Self-help group

KEY POINTS

- Early diagnosis can prevent disabilities and lead to a better health outcome.
- Exercises are essential to maintaining mobility and functionality.
- Developing a medication plan with a doctor in a cooperative and confidential manner supports a good health outcome.
- Patient organizations offer self-management and enable the exchange of thoughts.

THAT'S ME

October 2019

Age: 72 ([Fig. 1](#))

Weight: 86 kg

Profession: retired grammar school teacher/school director

Marital status: married, no children

Illness: ankylosing spondylitis (AS) for more than 50 years

HLA-B27 positive

Illness Status: October 2019

My spine is almost totally fused.

My current disease status has been influenced by 2 key events apart from my AS illness:

- In 2011, I fell on my back and broke several vertebrae. This meant 2 operations.
- I had osteoarthritis problems with my left hip for several years. A hip operation has reduced the pain, but numbness in the thigh and lack of mobility are key problems

HOW MY ILLNESS DEVELOPED

- Looking back, I was very athletic. I played handball in winter, in summer I enjoyed athletics, and in my free time I played soccer.

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Fig. 1. Author portrait: "That's me."

- When I was 16, I felt I had injured my right ankle after a long jump competition. I contacted different doctors and they all made different diagnoses. One orthopedic gave me corticoid injections several times that did not help in the long run. Within 3 months, then, after the first symptoms, my right knee and my left elbow were swollen, and I could not move them properly. From the first symptoms to the point I ended in hospital took 6 months.
- I stayed in hospital for 25 weeks; my body had totally changed due to intense corticoid therapy. Due to hospitalization and rehabilitation, I could not go to school for 1 year. My first diagnosis was rheumatoid arthritis (RA) (Fig. 2).
- The RA symptoms slowly disappeared, with ups and downs. At the beginning of my 20s, I suffered more from low back pain, my cervical spine hurt, and my mobility was again and again more limited.
- I was diagnosed with AS when I went to a rheumatology clinic in my mid-20s. I went to physiotherapy regularly; in summer, I went to a spa in Italy; my medication was indomethacin (Amuno) (Fig. 3).
- At the beginning of my 30s, I felt I had to change my therapy concept. So, I joined a self-help group that offered hydrotherapy and group physiotherapy courses, although it was quite far away from my home. I spent my summer holidays in a rehabilitation clinic (Fig. 4).

VOLUNTARY WORK

I have worked as a volunteer locally, on the national level, and for a couple of years for European League Against Rheumatism. Let me sum up the top questions that patients have asked me in consultation hours:

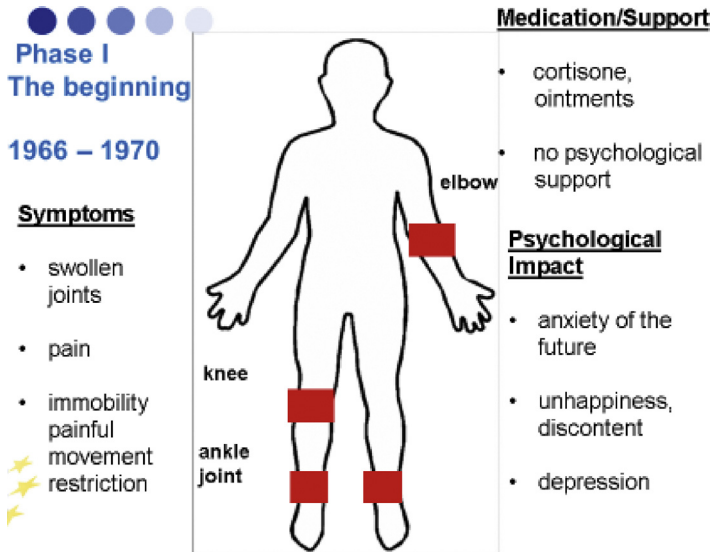


Fig. 2. Phase I, the beginning.

Q: Where do I find a good rheumatologist? Can you recommend one?

I always explained what options she/he has. When asking the patient after having consulted the rheumatologist, it is obvious what a good rheumatologist is as patients see it. This is someone who is competent, listens to the patient, communicates with the patient, and understands the illness impact on the patient's social life. The key points are competence and empathy.

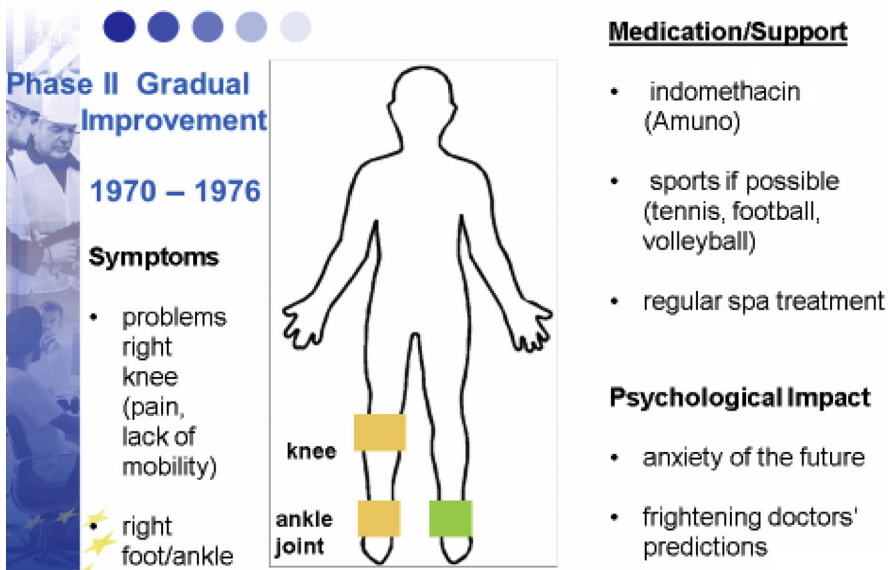


Fig. 3. Phase II, gradual improvement.

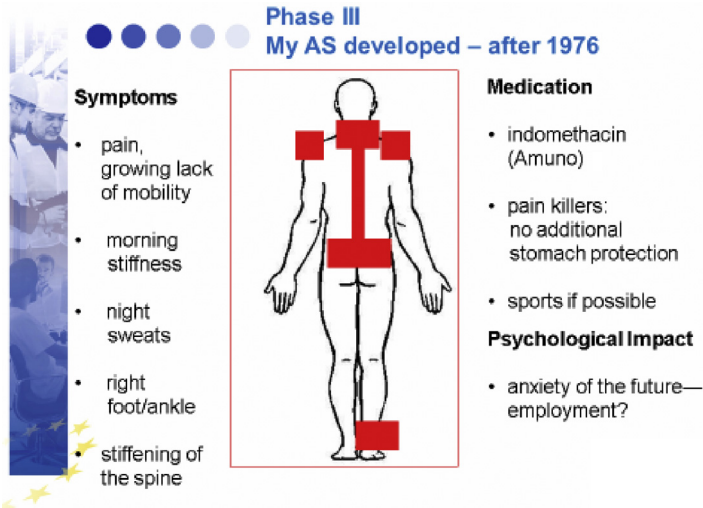


Fig. 4. Phase III, my AS developed.

Q: The medication my rheumatologist recommended has got lots of side effects; that scares me. What alternative medication is there causing less harm?

Lots of patients do not trust the medicine when reading the package insert and then consult nonmedical practitioners. I have always pointed out that due to inflammation there is the danger of irreversible physical damage.

Q: How can I influence my illness through nutrition? Is there a special diet for me? Can fasting cure me, because the inflammatory substances may then be washed away?

We have always offered different lectures about nutrition, diets, and fasting courses, where patients were supervised by a doctor. So, the message could only be: This is evidence-based and what we know, and just find out what is good for you.

Q: Should I notify my employer of my illness?

Disclosure is a very serious problem, especially for manual workers. Without any disability status and/or legal protection, there is the danger of being fired. The individual situation of the employed patient has to be explored. Job retraining and/or workplace adaptations have to be taken into account.

POINTS TO CONSIDER

In the following, a few key issues are outlined from a nonmedical patient perspective.

Late Diagnosis

In my case, it took several years until I received the right diagnosis. I do not want to complain, because this was in the 1960s. Data prove that even today a diagnosis often is made with enormous delay. There are many different reasons for this. But this long disease duration due to diagnostic delay has to be prevented, because only then will it be possible to avoid disabilities, optimize the health outcome for patients, and reduce costs for a country's health care system and economy.

All stakeholders in the health care system are challenged here.

Medical Therapy/Drug Treatment

Initially, in the 1960s, when doctors thought I had RA, I received high doses of corticoids that changed my appearance totally.

After being diagnosed with AS, I tried different nonsteroidal anti-inflammatory drugs and then took indomethacin for many years. From time to time, depending on the doses, I had serious stomach side effects. My voluntary work showed me that even in the 1970s and 1980s some doctors did not see the dangers of side effects on the stomach and did not prescribe proton pump inhibitors if needed, which is common today.

I only took a disease-modify antirheumatic drug for about 9 months (sulfasalazine), when I suffered from serious peripheral involvement (left ankle) and could hardly walk.

When cyclooxygenase-2 inhibitors got onto the market, I first took Viox; then, when it was taken from the market, I switched to Arcoxia, as needed.

I have never tried biologics because the inflammation is rather low and my pain is not due to any inflammation process. I know that for most patients biologics mean a new quality of life.

I think patients nowadays should be informed about medication opportunities; about the potential side effects, in particular the cardiovascular and gastrointestinal risks; and what measures can be taken to avoid or minimize side effects.

Another key issue nowadays is the switching of patients from biologic originators to biosimilars. According to my experiences, the switching is being done totally differently. Some doctors just maintain that the name of the product has changed; some give a sheet of paper that explains what a biosimilar is and why it is as good as the originator; and some doctors inform and even involve rheumatology nurses. I think it should be the aim that after information and education doctor and patient achieve a shared decision.

Eye Problems: Uveitis/Iritis

In the first 30 years after being diagnosed I suffered from a uveitis attack quite regularly, even often in my holidays when I was somewhere abroad. Pain and sensitivity to light forced me to consult a doctor. Only once, both eyes were affected.

Based on my experience and being aware of the symptoms, I now have the medication with me (steroid eye drops and dilating drops), especially when traveling in countries outside of Europe. I can only recommend that, in particular, when visiting less advanced countries. You have to consult an eye doctor for an eye examination, but the advantage is you can start with the medication and sometimes the eye doctor becomes superfluous, if the inflammation is not too serious.

Foot Problems

Foot problems have been common to me since diagnosed and have always been changing but have become less compared with the first 25 years of illness duration. Either pain under the heel and/or the arch and/or at the back of the heel caused serious problems in daily life.

So, for many years I only have only bought and worn shoes where I can use my orthopedic insoles and those shoes that possessed good shock absorbency.

I feel that we pay lots of money for all kinds of body lotions, perfumes, and so forth, but we neglect our feet that carry our weight all our life.

I would like to recommend caring for your feet, buying quality shoes, and using bespoke insoles, which I assume may be more difficult for fashion-conscious ladies.

Psychological Impact

When I was diagnosed with AS in a rheumatology clinic and was surrounded by patients with serious structural damage, irreversible spinal fusion, and different kinds of deformities, I felt depressed for months, although my illness was not obvious.

I remember a situation as a young teacher when I visited another school with colleagues to learn about team teaching. There I realized at once an elderly AS colleague in the teachers' room, his spine stiffened and bent forward. I swore to myself that I would not teach with this kind of health status and posture, because I remembered when I was a pupil how a handicapped teacher was ridiculed and teased by pupils, although, to my mind, his teaching was good.

Despite pharmacologic and nonpharmacologic therapies, I could not prevent the spinal fusion. It took me several years to cope with this changing of my body. Having accepted my illness at a certain stage, I felt much better; there was no use concealing my illness. For my pupils, my health status was never a talking point; the quality of my teaching and the way I supported them were essential. But there were great challenges. When entering the classroom for the first time and getting into contact with pupils for the first time, I had to radiate self-confidence and self-assurance and show that I was the boss.

I think if structural damages and deformities occur, a patient goes through different stages of coping strategies. These phases often are associated with pain, which increases the impact on the person's psyche. Lots of patients need psychological support to cope with their illness and manage these crises.

Hazards

Driving

For those with a (completely) fused neck, the ability to drive safely ([Fig. 5](#)) is seriously affected. I have always experienced that doctors do not touch this very relevant aspect of safety—safety for self but also for fellow citizens. A patient should check what support is useful, so that mobility can be preserved ([Fig. 6](#)).

Fractures

A couple of years ago, I slipped and fell onto my back. I broke several vertebrae; 2 operations caused a longer stay in hospital and rehabilitation ([Fig. 7](#)).



Fig. 5. Driving.

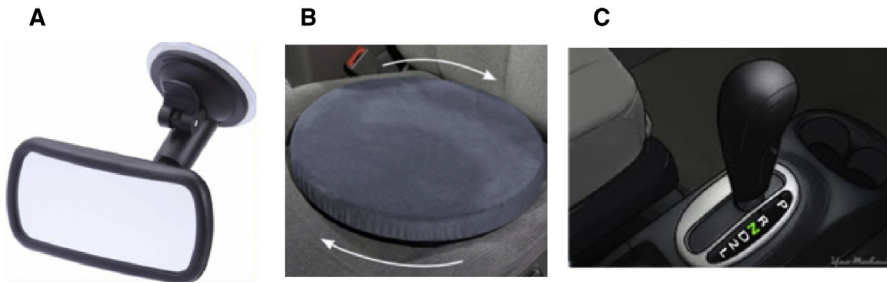


Fig. 6. Some helpers: (A) extra mirrors, (B) swivel car cushion, and (C) automatic transmission.

Aspects

It is a necessity to create awareness of the dangers implied when falling or in cases of a car crash.

Surgery

If the hips are affected, which happened to me as well, a hip replacement may be needed (**Fig. 8**). To my mind, good physical exercises before the hip replacement are essential for a good outcome.

Physical Therapy/Hydrotherapy

It is essential to do certain exercises every day like stretching, postural exercises, deep breathing, and different motion exercises for the spine. Ideally, it is good to learn a program of 15 minutes to 20 minutes and practice these exercises every morning.

As we all know how difficult it is to achieve sustainability and overcome laziness, it is of great help to join a patient group once or twice a week. Doing these exercises in a group with a qualified physiotherapist means fun, and this improves mobility, reduces stiffness and pain, and often even helps to sleep much better.

There are times, however, when it is needed to consult an individual physiotherapist, especially at times of flares.

Fatigue

Again and again, fatigue has been a serious problem for me and I know it is relevant for lots of patients. I was quite lucky because I often could set up my daily routine

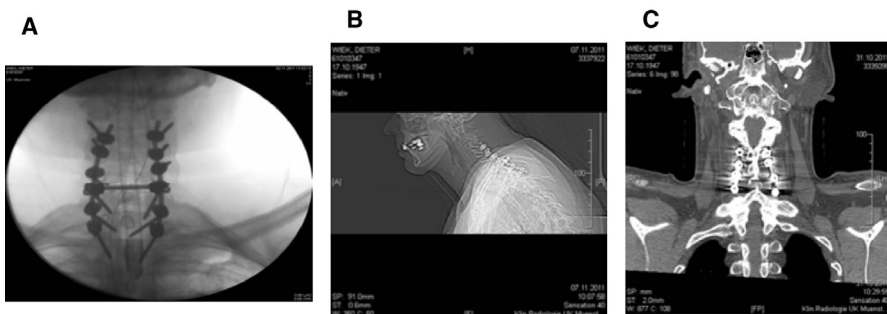


Fig. 7. (A–C) Vertebrae fractures radiographs.



Fig. 8. Hip radiograph.

accordingly. A lot of different factors like sleep disturbances, pain, physical limitations, and feeling depressed contribute to fatigue.

Rest periods and relaxation techniques but also exercises and fresh air help overcome this tiredness. Employers should be aware of this problem, allow short breaks, and see that the AS patient's overall performance will not be less.

Working with Ankylosing Spondylitis

When I got ill at the age of 17 and had very difficult health issues in my 20s, it was my top priority to have a qualified job that enabled me to organize at least a part of the day according to my needs. And that is what I always communicated in consultation hours: for young people seriously affected, a professional qualification is the best way of getting into a job and staying in work. This is crucial for a successful life. It means income, recognition, acceptance, and being an integrated member of society.

When the disease progresses, workplace adaptations may be needed, more working time flexibility and so forth, but with reasonable adjustments, there is a good chance of staying well in work.

Self-Management

Nowadays we live in an information age; smartphones enable access to endless information and make it possible to communicate with others affected.

Nevertheless, I personally believe that it is quite useful to join a self-management course. It is essential to learn about

- Medication options
- Nonpharmacologic interventions
- Comorbidities
- How AS can affect joints, eyes, or other parts of the body
- Why breathing exercises are so important and smoking is not good for you
- How working with AS can be managed

These are just some relevant examples that contribute to better self-management.

Patient Organization—Should I Join?

I have been engaged in a patient organization for more than 30 years. There are good reasons for joining:

- Most organizations offer regular gym exercise groups and/or hydrotherapy, self-management courses, and so forth.
- When attending these activities, you talk to people who understand you and you exchange your views and experiences with them.
- You are updated about research and the most effective treatment.
- With your membership you support the organization's campaigning and lobbying activities for better health care for AS patients.

DISCLOSURE

Nothing to disclose.