

Wrightington, Wigan and Leigh NHS Foundation Trust



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your hospitals, your health, our priority

What research told us



- Main determinants of health and illness depend more upon lifestyle, socio-cultural environment and psychological (personal) factors than they do on biological status and conventional healthcare.¹
- Work: is the most effective means to improve wellbeing of individuals, their families and their communities.²

Why worry about work?



- AS/Axial SpA typically affects people from a young age
- Has a detrimental impact on health and wellbeing
- Associated with significant risk of limiting work productivity over the life course
- Little attention has been paid to issues regarding work productivity

Urgent need to...

- Understand better the different perspectives of people with AS/axial SpA and to...
 - Understand better the different perspectives of health professionals, of health service managers, and of employers

AND also to embed issues pertinent to work productivity as a routine element of healthcare



Not a small problem

Approximately 200,000 people have AS in the UK³



- Many years may pass between the first symptoms and a definitive diagnosis 4.5.6
- About 50% of people with AS develop associated disorders, including episodic iritis (40%), psoriasis (16%) and inflammatory bowel disease (10%)⁸

Impact on personal development and attainment



- Commonly begins in adolescence or early adulthood
 - critical time in terms of education, work and establishment of social frameworks and relationships
 9
- Typically advances slowly, often leading to insidious decline in physical and social abilities, whilst comorbidities may also develop
- Outcome is largely unpredictable, and the degree of disability ranges from minimal to devastating ¹⁰
- Poses problems in relation to the person's career, family and social life ¹¹

AND.....



- Pain, stiffness, fatigue and sleep problems are important concerns
- Can lead to changes in mood or personality, low self-esteem, stigma and worry about the future ¹²
- Can experience a wide range of additional problems, including the psychological distress of having to 'fight' to get a diagnosis
- Made worse by the lack of familiarity and knowledge of AS/axial SpA amongst healthcare professionals and the general population

Impact on work productivity

Responsible for substantial direct and indirect socioeconomic costs, work disability ^{13, 14, 15} and impact on quality of life ^{16, 17}



- Withdrawal from work is three times more common in people with AS than in the general population, increasing from 5% during the first year of diagnosis to over 20% at 10 years and 30% at 20 years ^{13, 14}
- One-third of hospital attenders with AS give up work before retirement age and others modify or reduce their work ¹¹
- 50% of people with AS experience work instability, whilst 15% reduce or change their work because of AS



Impact on work productivity

- Loss of employment is associated with being older, longer disease duration, lower educational achievement, co morbidity, greater physical impairment, pain, fatigue, stiffness, anxiety, depression and lower self-esteem 11
- People experience significant personal and societal costs that rise substantially with decreasing function ¹⁸
- AND....People with non-radiographic axial SpA experience a similar burden of disease and impact on health related Quality of Life as those with established AS 19, 20

Key determinants of work productivity



- Paucity of literature
- Most framed as questionnaire surveys 21,22, 23, 24, 25, 26
- Concluded that the determinants are complex and multifactorial
- Issues identified encompass a range of socio-cultural, psychological, coping, lifestyle and occupational factors.

Physical features pertinent to a person's ability to remain in work

Loss of spinal mobility and chest expansion



Many people with AS experience continuing decline in spinal mobility even after 20 years of disease ²⁷ independently of disease duration and reported frequency of unsupervised exercise ²⁸

Moreover, failure to prevent disease progression leads to about 40% of people eventually developing severe spinal restriction 29

Features that may affect people within the work place

- Pain and stiffness
- Sitting in a static position
- Problems with mobility sometimes involving peripheral joints
- Tiredness due to sleep disturbance and/or fatigue with consequent impact on the ability to concentrate
- Depression can be strongly associated with unemployment outcomes including absenteeism and presenteeism ³⁰





The 'stigmatisation' of having 'back pain'

- May negatively influence willingness to disclose symptoms and working difficulties to managers and work colleagues alike
- The workplace is a difficult arena in which to maintain relationships by trying to remain 'normative in the face of disruption'
- People may experience pressures from work colleagues who may be reluctant to redistribute the workload
- Frequent absences have been identified as limiting work colleagues' tolerance levels ³¹

Financial and personal costs of living with AS

Substantial 32.....

Cost of drugs and other treatments



- Regular exercise
- Increased insurance premiums
- Reduced earnings and pension rights which can ultimately lead to financial disadvantage

Cost to society

Potential loss of up to one third of people with AS from the workplace



May fail to achieve their chosen career or to fulfil their potential ³³ Loss of tax revenue from those patients and carers unable to work, and the cost of paying disability benefits and/or benefits to carers allowance

The direct costs of treatment include primary and secondary care costs, drug costs and social care costs with societal costs rising steeply as physical function deteriorates.

Raising awareness about work productivity

- NASS 'Looking Ahead' document emphasised the role of delay in diagnosis and lack of awareness of the condition from family, friends and employers
- 2009 survey Only 12 per cent reported that AS had made no discernible impact on their working lives
- One third reported that they were able to perform less physical or manual tasks at work than before the onset of AS.





NASS 2009 survey

- Not receiving useful advice from healthcare professionals or employers on how to cope with their condition at work and that work related issues were often not even discussed
- Had waited too long to receive a diagnosis and this had impacted on their productivity
- Effective treatment made a significant difference to being able to remain in work
- People with more severe AS reported more impact on their working lives and those with higher disease activity were twice as likely to report that their working life had been affected

NASS 2009 survey

- 61 per cent were concerned about the impact of the deterioration of their condition on their job or employment prospects
- 30 per cent had concerns about discrimination because of their AS, from employers or colleagues
- Two-thirds reported that they occasionally went to work despite feeling unwell.



NASS 2009 survey

Those who found their treatments helpful had fewer perceived barriers to remaining in employment than those whose treatment was not working well.

They were less likely to report pain and fatigue affecting their ability to work and were less likely to need time off sick.





The '2020 Health' report 35

Recommends that....

- Employers should be encouraged to develop strategies for getting people back into work
- Small businesses should be encouraged to work with larger organisations to exchange ideas and best practice





'Rather than employers being dismissive of complaints about back pain or viewing them with suspicion as an excuse for poor performance, it is important for them to seek to improve the working lives of people with long term conditions so that they remain in work."

Key areas for employers to give greater attention

- Providing appropriate training for co-workers to enable them to support employees with long-term conditions.
- Adapting a flexible approach to job design and responsibilities, which may include flexible working hours, amended job descriptions and inclusive recruitment policies and procedures
- The benefits of allowing employees with AS to take regular short breaks from work to stretch out and exercise was highlighted
- Proactively engaging with healthcare professionals (such as GPs and occupational health) when an employee notifies them of their condition, so that the individual is able to remain an effective member of the workforce without feeling isolated.



The Work Foundation

- Report on the impact of AS on work in the UK ³⁶
- Highlighted the potential for AS/axial SpA to significantly disrupt or even curtail the participation of younger people in the labour market, adding further to the case that there are important clinical, social and economic benefits of keeping people with AS/axial SpA in work.



Tools to measure impact of AS/axial SpA on work



Capturing the impact of the condition on a person's work ability is not currently a core component of health assessment, partly because there is a paucity of tools to measure its impact on working lives.

Work advice and support

- Maintaining a healthy posture
- Avoiding working or sitting in a hunched positions
- Avoiding reaching high up over head if a kyphotic posture is present





- Using ergonomically correct desk chairs to support the entire spine
- Requesting more flexible hours if fatigue is a problem
- Advice on lifting techniques and general back care



- Workplace adjustments
- Flexible working arrangements
- Exercise regimes and physiotherapy can be beneficial to achieve this

NASS 'AS it is' Survey 1,630 responses

Are you currently in employment?			
Yes, full time	39%		
Yes, part time	14%		
No, in education	1%		
No, full time parent	2%		
No, retired	29%		
No, not able to work due to health	15%		

NASS 'AS it is' Survey 1,630 responses

What impact, if any, do you think your AS has had on your working life?				
Had a very negative impact	35%			
Had a slightly negative impact	42%			
Has not really impacted either way	14%			
Had a slightly positive impact	2%			
Had a very positive impact	4%			
Don't know / not sure	3%			

NASS 'AS it is' Survey 1,630 responses

Which would you say comes closest to your feelings about your current household income?

Living really comfortably on current income	9%
Living comfortably on current income	32%
Neither comfortable nor struggling	33%
Struggling on current income	14%
Really struggling on current income	7%
Don't know / Prefer not to answer	6%

Consequences of 'AS it is'

- Called for NHS England to recognise important work-related issues associated with AS, including encouraging health professionals to discuss work issues during routine appointments
- Advocated that people with AS should have regular access to the expertise of occupational therapists





NASS 'Managing your AS at Work: answers and practical advice'

- How to talk about AS at work and how to stay well at work
- Recommendations for work station assessments, maintaining good posture, keeping active, prioritising tasks and pacing techniques.
- Cites The Equality Act 2010 and advice about taking time off for medical appointments.



'Employers Guide'

- Describes what AS is and how it can affect a person at work
- How employers can provide support
- Points out that AS is covered within the Equality Act 2010.

Advisory Fitness for Work Report Allied Health Professions Federation (AHPF) 37



- UK professional bodies of physiotherapy, occupational therapy and podiatry
- Objective of enabling people to safely remain in or return to work wherever possible.
- Assesses functional difficulties in both the clinical and work place settings to provide the most appropriate solutions
- Should be completed with assistance from a suitably qualified AHP.

Advisory Fitness for Work Report



- Addresses aspects of phased return
- Altered hours
- Amended duties
- Work place assessment with the employers' agreement
- There is also emphasis on specific patient reported work-related difficulty with recommendations and goal setting within the work place
- Classified as 'advice' and is not a replacement for the Statement of Fitness for Work (Fit Note) for benefits purposes.

Effects of biologic treatments on work productivity

- Efficacy has been widely demonstrated in several large scale multi-centre studies 38, 39, 40, 41, 42 43
- Biologic treatments clearly offer strong potential for individuals to benefit significantly in terms of enhanced work productivity
- Large cohort studies are currently underway to determine whether such benefit is also demonstrable
- Excellent opportunities to harness the potential offered by advanced treatments and technologies to improve work outcomes



So what actually happens in the here and now?

These guys are great

- Prof Sayeed Khan and Prof Debbie Cohen Cardiff University funded by the Fit For Work coalition
- Deliver training to increase knowledge, skills and confidence for the rheumatology team in managing clinical issues relating to work and health
- Its all about providing practical tips and strategies to use when talking to patients
- Understanding better what people do, motivational interviewing, signposting



Fitness for work: health on work



- Mobility: walking, bending, stooping
- Agility: dexterity, posture, co-ordination
- Rational: mental state, mood

Stamina

- Treatment: side-effects, duration of
- Intellectual: cognitive abilities
- Essenial for job: food handlers, driving
- Sensory aspects: safety self and others

'Working it out' A longitudinal qualitative study concerning work issues in newly diagnosed AS/Axial SpA 43

We aimed to conduct a longitudinal in-depth exploration into experiences in newly diagnosed participants both at diagnosis and a year later. We sought to gain insights into experiences of pre and post diagnosis highlighting both the positive and negative impacts perceived whilst working with this condition



- Ethical approval was obtained for a qualitative phenomenological study embedded within a longitudinal cohort study of people newly diagnosed with AS/AxialSpA in the UK.
- 10 participants from 2 sites meeting the inclusion criteria, gave consent to be interviewed at diagnosis and one year later utilising an in-depth semistructured approach. The Interviews were recorded, transcribed verbatim and analysed thematically using a Framework analysis.
- A systematic and rigorous approach was used to ensure that codes, code frameworks and themes were grounded within the data, and were credible and trustworthy.

Results

- Ten participants (7 male, 3 female) with an average age of 40.2 years who had recently been diagnosed with AS/axial SpA participated in the study
- They reported that the number of years of symptoms before diagnosis to be an average of 10.1 years.



Demographic characteristics of participants					
Participant	Gender	Age (yrs)	Social status	Employment status	
P1	Female	26	Single	F/T Personal Assistant for her brother	
P2	Male	47	Married	F/T Policeman (Custody Sergeant)	
P3	Male	49	Married	Self Employed Electrician	
P4	Male	36	Married	F/T Postman	
P5	Male	32	Married	F/T IT predominantly working from home	
P6	Male	42	Married	Was F/T Butcher but on sick leave at interview 1. Became a self employed window cleaner by interview 2	
P7	Female	47	Divorced	P/T Dental Nurse	
P8	Male	32	Married	F/T IT Manager	
P9	Female	41	Married	F/T Teaching Assistant. Part-time counsellor and a hypnotherapist in the evening	
P10	Male	47	Divorced	F/T Factory Worker assembling garage doors and shutters	



Implications

- Living with a diagnosis for a year provides reinforcement of the benefits gained by the positive intuitive changes and adaptions made pre diagnosis.
- Participants had been able to 'sense' what to do and realised 'what works' in regard to maintaining the expectations for their job role resulting in feelings of empowerment.
- Diagnosis gives legitimisation to remaining as active as possible within the work place although this was tempered with issues of disclosure to colleagues and/or managers as to why this was essential.
- Even with a diagnosis it appears that a risk/benefit assessment continues to be made as to the level of disclosure that participants are prepared to make which was dependent on individualised circumstances.
- There is frustration associated with the lack of understanding of what AS/Axial SpA is coupled with a fear of stigmatisation.
- At diagnosis clinicians should not underestimate the positive adjustments that people are intuitively making and need to reinforce these adjustments accompanied with an appreciation about the lack of awareness of this 'invisible' condition



'Working it out'

The conversation

The outcome







Thank you



We don't learn from talking; we learn from listening.

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