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McCluskey, Serena

The role of 'significant others' in vocational rehabilitation for patients with persistent back pain

### **Original Citation**

McCluskey, Serena (2013) The role of 'significant others' in vocational rehabilitation for patients with persistent back pain. In: The British Pain Society Pain Management Programmes Special Interest Group 14th National Conference, 25-27 September 2013, Jersey, UK.

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# How significant are ‘significant others’?

*Are the illness beliefs of family members  
psychosocial obstacles to work participation for  
patients with chronic low back pain?*

**BackCare**  
The Charity for Healthier Backs

Registered as National Back Pain Association Charity No: 256751

**BupaFoundation**  
The Medical Research Charity

McCluskey et al., BMC Musculoskeletal Disorders, 2011;12, 236  
Brooks et al., BMC Musculoskeletal Disorders, 2013; 14, 48

# Background

- Long-term sickness absence and disability benefit rates continue to increase across industrialised countries
- OECD countries spend 0.8% of their GDP on sickness absence benefits and 1.2% on disability benefits
- Only 2% of those in receipt of disability benefit return to work
- Back pain a leading cause of sickness absence and work disability

# Background



- Back pain at work accounts for 9.5 million days of sickness absence
- Persistent back pain (longer than 3 months) accounts for 20% of disability benefit claims
- Majority who have been on prolonged sick-leave will not return to work

100%

Proportion of people **not** recovered or returned to work

### Standard recovery curve for musculoskeletal problems

The first part of the curve is quite steep, illustrating that many people recover or return to work within days or weeks. But, as time passes, the recovery curve flattens showing the mounting effect of obstacles – people then find it increasingly difficult to recover and get back to work.

### Improved recovery curve

Effectively identifying Flags and tackling the obstacles will squash the curve. The effect will be increased recovery rates, leading to reduced sickness absence and less long-term disability.



# Why do some people become disabled?

- They do not have a more serious health condition or more severe injury
  - So, it's not about what has happened to them; rather its about why they don't recover
- They face **obstacles** to recovery and participation



# The obstacles model

- obstacles to work participation



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→ biopsychosocial approach



# Psychosocial Flags Framework



**Person** - psychosocial factors associated with unfavourable clinical outcomes and the transition to persistent pain and disability

**Workplace** - stem largely from perceptions about the relationship between work and health, and are associated with reduced ability to work and prolonged absence

**Context** - in which the person functions; includes relevant people, systems and policies. These may operate at a societal level, or in the workplace. They are especially important since they may block the helpful actions of healthcare and the workplace



# Important flags to identify - **Person**



- **Thoughts**

- Catastrophising (focus on worst possible outcome, or interpretation that uncomfortable experiences are unbearable)
- Unhelpful beliefs and expectations about pain, work and healthcare
- Negative expectation of recovery
- Preoccupation with health

- **Feelings**

- Worry, distress, low mood (may or may not be diagnosable anxiety or depression)
- Fear of movement
- Uncertainty (about what's happened, what's to be done, and what future holds)

- **Behaviours**

- Extreme symptom report
- Passive coping strategies
- Serial ineffective therapy

# Illness perceptions

- Illness perceptions (defined as the processes by which an individual's own implicit, common-sense beliefs about illness are associated with behavioural responses employed to manage outcomes) have been highlighted as important influences on clinical outcomes for back pain (*Foster et al 2008; 2010*).
- Further evidence suggests that illness perceptions may play an important role in mediating between illness and work outcomes (*Hoving et al, 2010*).



# Important flags to identify - **Workplace**



- **Employee**

- Fear of re-injury
- Low expectation of resuming work
- High physical job demand (perceived or actual)
- Perception of high mental job demand ('stress')
- Low job satisfaction

- **Workplace**

- Lack of job accommodations/modified work
- Lack of employer communication with employees
- Low social support or social dysfunction in workplace

# Important flags to identify - **Context**

- Unhelpful policies/procedures used by company
- Line manager competencies
- Process delays
  - (e.g. waiting lists, claim acceptance)
- Role ambiguity or disagreements between key players
  - (employee <> employer <> healthcare)
- Financial, compensation or legal issues
- Significant others with negative expectations or beliefs

# Significant others and work participation



- Department for Work and Pensions, UK (2011) – “family has an important role to play in facilitating RTW”
- HSE, UK (2013) ‘A spouse or partner acting as a proxy respondent is associated with a 26% reduction in the likelihood that an individual is recorded as suffering from work related ill-health. This increases to 53% where the proxy respondent is not a spouse or partner’
- Involving significant others provides a more in-depth understanding of the social factors involved (black flags)

# The influence of 'significant others'

- Illness perceptions, in particular, those of 'significant others' (spouse/partner/close family member) are rarely explored in relation to persistent back pain and work participation specifically
- Several studies suggest that significant others have an important influence on an individual's pain behaviour and disability

# Studies

- Chronic back pain patients and their significant others (n=28) in the North of England: (1) a Condition Management Programme; and (2) Hospital-based pain clinic
  - (1) all disability benefit claimants
  - (2) half disability benefit claimants; half remained at work
- Patients and their significant others were interviewed separately in their own homes, using an interview schedule derived from the chronic pain version of the Illness Perceptions Questionnaire (Revised) (IPQ-R) (*Moss-Morris et al, 2002*)



# Illness Perceptions Questionnaire



- 9 subscales

(1) illness identity; (2) timeline (acute/chronic); (3) timeline (cyclical); (4) consequences of illness; (5) personal control over illness; (6) treatment control; (7) emotional representations, (8) illness coherence; (9) beliefs about causality

# Interview questions

- What do you think was the cause of your relative's problem?
- What do you expect is going to happen?
- How effective is their treatment plan?
- When do you think they'll get back to work?
- What has been the effect on you?
- What do you think should be done to help?



# Data Analysis

- Data were analysed using template analysis (*King et al, 2002; King, 2004*)
- A-priori themes arranged around the nine subscales of IPQ-R
- Initial template was constructed using the significant other interview data, mapping on patient data

# Participants



- Mean age: claimants = 48 years; significant others = 50 years  
working = 49 years; significant others = 37 years
- Gender: majority claimants = male; majority significant others = female
- Majority claimants previously worked in manual occupations, majority of working were in managerial or professional occupations
- Majority of claimants had not continued their education past school-leaving age; majority of those in work had continued their education
- Majority of dyads=spouse/partner, other were parent/child relationships

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# Results:

- When the final template was produced, it was found that those IPQ-R constructs most relevant to work participation were:
  1. *Beliefs about causality;*
  2. *Consequences of illness;*
  3. *Treatment expectations*
- Two additional themes were uncovered:
  4. *Patient/claimant as genuine;*
  5. *Being a good significant other*

# Results – ‘Beliefs about Causality’

*“I didn’t have any problem with it up until going into that job and that’s why I’ve put it down to doing those things....if I’m in a job where I’m sitting down all day or standing or whatever at a machine all day then it’s going to go, it’s going to continue to go”*

*[Claimant]*

*“It’s probably something that he carried in work that hurt his back”*

*[Significant other]*

# Results – ‘Consequences of illness’

*“What’s important is that I’m not sat down or stood still or something like day after day because it’ll stop me from walking, which will stop me from working”*

*[Claimant]*

*“And, as I say to him, who’s going to hire you? With a backache, you know.....And who’s gonna let him lie down when he’s working in the factory, no-one are they?”*

*[Significant other]*



# Results – ‘Claimant as genuine’

*“I’ve always worked since I came out of school ..... well I carried on working in the evenings when I was at school and not being able to work has crippled me. I had three jobs at one time; I was working in three jobs, and to go from three jobs to nothing...”*

*[Claimant]*

*“I can probably tell when I can see the way he walks if he’s sore or not”*

*[Significant other]*

# Results – ‘Being a good significant other’



*“I just help him, run up and down stairs when he wants....if he wants something he can ask me and I’ll do it for him”*  
*[Significant other]*

*“Maybe we’re an odd household because we’re both ill – that makes us more understanding of each other”*  
*[Significant other]*

# Summary of findings

- Significant others shared and further reinforced unhelpful illness beliefs of claimants
- Significant others more resigned to permanence and negative inevitable consequences
- Significant others more sceptical about the availability of suitable work and sympathy from employers
- Claimants were keen to stress their 'authenticity' and significant others acted as a 'witness to pain' or were overly solicitous – good significant other

# Non working vs working: 'Beliefs about causality'

- *"I know for a fact it was work because she complained doing it"*

*[Significant others of claimants]*

- *"He goes to work because he just won't give in to it making him an invalid"*

*[Significant others of working]*

# Non-working vs working: 'Consequences of illness'

- *“How can he get a job with his back the way it is, when he can’t sit down too long, he can’t walk too long, he has to lie down?”*

*[Significant other of claimant]*

- *“He doesn’t not do anything because he’s got pain”*
- *“I think his mental attitude is probably the reason he works full-time”*

*[Significant others of working]*

# Non-working vs working: 'Treatment expectations'

- *"We've tried everything and nothing works"*
- *"They didn't do everything they could....I think back pain seems to be at the bottom of their list"*

*[Significant others of claimants]*

- *"It's accepting that they can't actually do anything more and you just have to live with it"*

*[Significant other of working]*

# Working vs non-working: 'Patient/claimant as genuine'

- *I could see how much pain he was in ... even sitting down for more than half-an-hour"*

*[Significant other of claimant]*

- *"He pushes himself to go to work every single day. He's not collecting benefits...he's trying to do something to help himself"*

*[Significant other of working]*



# Non-working vs working: 'Being a good significant other'

- *"I know what he's going through....whatever he needs, I'm willing to do it"*
- *"I wait on her hand and foot when she's bad"*

*[Significant others of claimants]*

- *"She manages herself remarkably well"*
- *"He has an amazing pain threshold, such determination"*

*[Significant others of working]*

# Treatment Expectations

- *‘Cure’ vs ‘pain management’*
- *‘Feeling abandoned’ vs ‘no-one’s fault’*
- *‘Waiting for an answer’ vs ‘carrying on regardless’*

# *‘Cure’ vs ‘pain management’*

*“All I know is she’d like a cure  
to be able to get back out  
there and get back to work”*

*[Significant others of claimants]*

*“The epidurals are every 6  
months, and with them she  
can manage to work”*

*“Pain management is our  
preferred option”*

*[Significant other of worker]*

# *‘Feeling abandoned’ vs ‘no-one’s fault’*

*“They didn’t examine him, just asked questions, gave him tablets and out you go...sometimes it’s anger at the doctors more than anything else”*

*[Significant others of claimants]*

*“I don’t think the doctor will fully understand it, no-one does”*

*“Doctors don’t like not being able to make things better”*

*[Significant other of worker]*

# *‘Waiting for an answer’ vs ‘carrying on regardless’*

*“She wasn’t happy with the results....there is something else underlying and we are waiting to see”*

*“She’s only been referred to a pain management clinic because she pushed for it...she should have had this years ago”*

*[Significant others of claimants]*

*“He’s definitely not sitting around doing nothing because he’s got a back problem”*

*“He goes to work because he just won’t give in to it making him an invalid”*

*[Significant other of worker]*

# Summary

## *Claimant 'significant others'*



- Expected a cure;
- For patients to be pain-free in order to resume work;
- Felt abandoned and not believed by healthcare professionals;
- Were waiting for the 'correct' diagnosis to be made before RTW

*Journey through the healthcare system was recounted and used to validate ineffectiveness of treatments offered and options available*

# Summary

## *Worker 'significant others'*



- Were more accepting of their relative's condition and positive about pain management;
- Understood that healthcare professionals did not have all the answers;
- Believed that their relatives continued to work because they did not want to be defined or disabled by their condition

*Overall, this sample did not perceive their relatives as 'ill'*



# Summary: working sample

- Significant others focused on what the patient could still do
- Significant others talked about patients as 'heroic' in their efforts to remain at work
- Significant others did not 'blame' work for the cause of the condition
- Significant others were supportive of the patients efforts in continuing to participate in normal activities, suggesting they were 'good' patients
- Significant others did not expect the back pain to be cured, but were positive about effective pain management
- Significant others had a greater degree of acceptance

# Conclusions

- Significant others have similar and in some cases, stronger beliefs than patients about treatment for persistent back pain and work participation (helpful and unhelpful!)
- Significant others could be valuable resource
- Wider social circumstances need to be acknowledged as obstacles or facilitators to work participation
- Focusing on the individual as the sole target for intervention may not always be appropriate/effective

# What should we do?



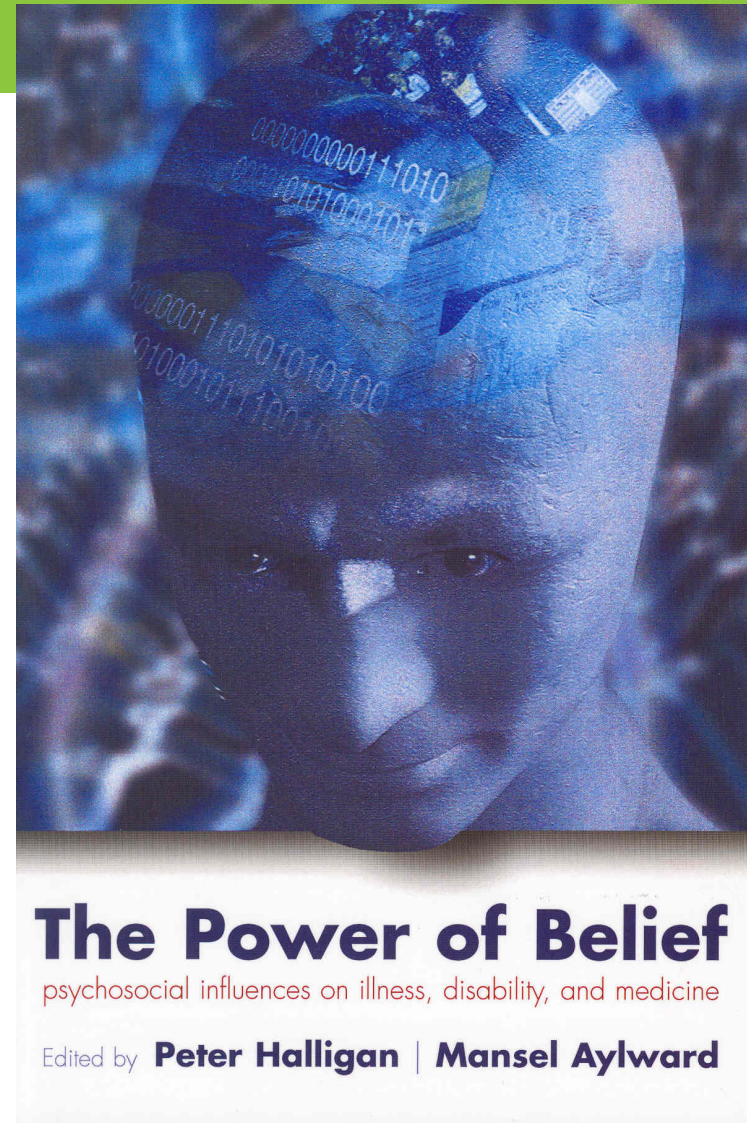
- Early intervention
  - identify and address obstacles
  - myth busting info
- Healthcare: *work-focused*
  - deal with bio issues whilst supporting early RTW
  - psychosocial problem-solving

# Challenging beliefs

- Beliefs are central to what we do about injury and disease
- Health myths abound
  - held by clinicians also!
- Myths are major obstacles to work participation

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# Myths:

*It's a health problem, so  
there must be a cure....*

*Rest always needed  
until pain goes*

*Working whilst ill or  
'injured' will just make  
matters worse*

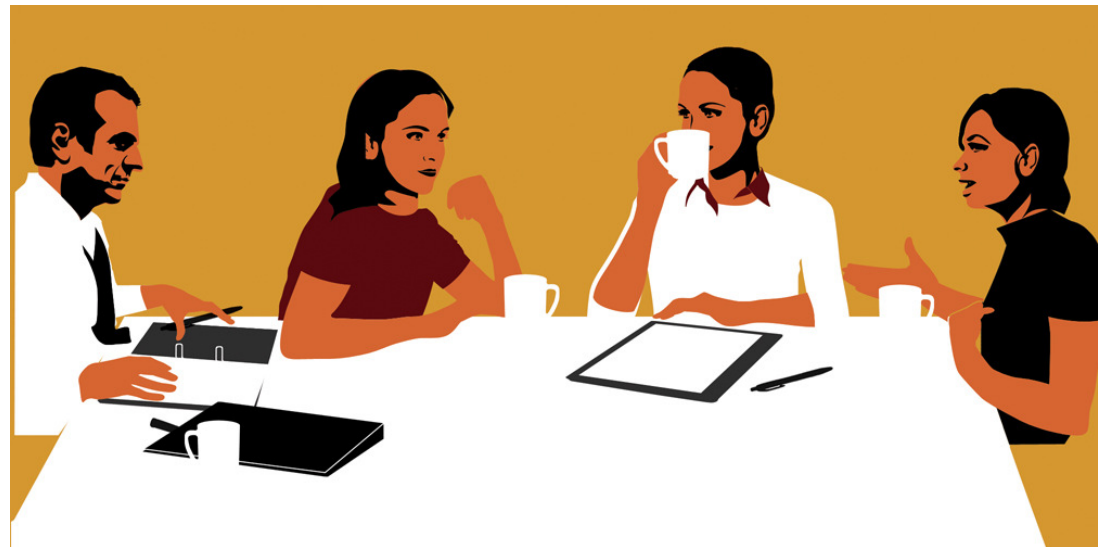
*It hurts at work, so I  
was damaged by my  
work*

*Contacting absent  
worker is intrusive*

*No return to work until  
100% fit*

# Key players must be onside and acting

- Poor communication is a major obstacle
  - Information, for all the players, needs to be:
    - consistent
    - accurate
    - unambiguous
    - pertinent
    - understandable





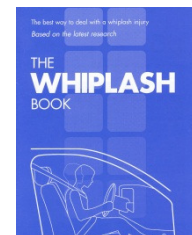
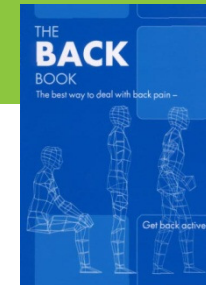
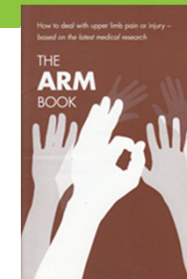
# Dispelling myths and shifting the culture



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- 3 evidence-informed leaflets
  - workplace
  - worker
  - healthcare
- Evidence-informed
- Practical advice on return to work processes
- Facilitate communication and understanding
- Synchronous distribution
- Free PDFs



Advice for workers with muscle and joint problems helping you to stay active and working

**Important information**

- Activity and work are good for physical and mental health
- Muscle and joint problems are very common - pretty much everyone has them at some stage during their life
- These problems can be distressing and may make life difficult for a while
- Serious disease or injury with lasting damage is very rare
- Most episodes settle quickly, but the symptoms may crop up again
- It's best to stay active and continue working, or get back soon

**1 make a plan to be active and working**

The key is communication and action. There are two main issues:

**Recovery** depends on working with the health professionals who are helping you, and on your own motivation and effort. Treatment can help to reduce your symptoms, but you are the one who has to get back to work - see activity as part of your treatment.

**Ask yourself:** What can I do to be a 'looper' and not an 'involider'?

**Returning to work** depends on you and your employer working together, and that needs communication. The key thing is to stay in touch with the people at work - figure out what's needed to help you return.

**Ask yourself:** What obstacles are getting in the way of my going back to work, and who do I need to talk to about overcoming these (through problem-solving and negotiation)?

**2 identify obstacles to your recovery**

Various things can get in the way of recovery and getting back to work and activity.

**Personal obstacles** involve how you feel and think:

- Unhelpful attitudes and beliefs about health and work
- Uncertainty
- Anxiety and depression
- Loss of routine and work habits

**Work-related obstacles** can block your return to work:

- Loss of contact with work
- Negative attitudes by people at work
- Lack of job accommodations or modified work
- Misunderstandings and disagreements between you, your employer, and healthcare professionals

**Health-related obstacles** can confuse and delay:

- Conflicting advice
- Waiting lists
- Prolonged sick leave
- Ineffective treatments

**things to watch out for**

You are unlikely to recover and return to work if you:

- Believe there is something seriously wrong
- Are unable to accept reassurance and help
- Avoid activity in case it makes things worse
- Get withdrawn and depressed
- Are fearful and uncertain about going back to work

The longer you are off work or not doing your usual activities, the harder it is to get back.

**3 make a plan to be active and working**

**action!**

**Putting your plan into action:**

Take control - Take responsibility for your recovery, making best use of available help.

Set realistic goals - Give yourself a clear timeline for getting back to work and activity. Use weeks, not months.

Get what you can do - Have a 'can-do' approach, and avoid dwelling on what you can't do easily at present. You'll find you can do a lot of things - at work and leisure.

Talk with your health professional - Discuss what you can do work out ways to get active and back to work. Give them permission to talk with your employer.

Increase activity - Do a little more each day for a little longer. Pace yourself - do no more on good days and no less on bad days.

Changing your attitude and improving motivation - Don't get gloomy or anxious. Getting active will improve your confidence and you'll feel more positive.

Talk with your employer - If your employer has not been in touch, make the first move. Temporary changes to your job are one of the best ways of making it possible to get back to work, not least what's needed with your line manager.

Put it all together - Make sure that you and your doctor and your employer all know what's happening and what you are planning. Tell them you want help to be a co-per.

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# Significant others: what should we do?



- Modified versions of available tools/advice?
- What is feasible? Address treatment expectations/beliefs about illness? Sig other experience of illness
- What do clinicians/healthcare professionals need?
- Does addressing social influences require a public health approach? Target subgroups of the population? (i.e. high risk=low socioeconomic status/occupation)