



How does arthritis sit alongside gender stereotypes such as the tough bloke and the graceful lady? **Juliet Stephens** investigates whether having arthritis challenges perceptions and feelings of masculinity and femininity

Playing a gender role

Only a hundred years ago, men were supposed to be strong and macho, and women dainty and light. Not much scope for the variety of human experience there. Whilst gender stereotyping is inevitable, it is rarely helpful.

Fifty years on, gender roles have shifted enormously and, with the rise of both feminism and the emergence of the 'new man', messages around gender can now be confusing. Throw the reality of living with a long-term condition in the pot and things become even more complex.

'The traditional role for man is that he can cope with anything, irrespective of obstacles or adversity – he is Superman, basically,' says Phillip Hodson, fellow of the British Association for Counsellors and Psychotherapy, who has been a practising psychotherapist for over 30 years. How often are men punched on the arm in a stressful situation and told to 'be a man' and not cry?

Men are not encouraged to talk about their feelings because it is perceived as a sign of weakness and

vulnerability – although this behaviour is changing slowly. Living with arthritis means having to accept that sometimes you need to depend on others. 'The most challenging thing for me was – and still is – to ask for help. I felt reduced to a pre-school child, having to ask someone to put my shoes and socks on,' says James Ashmore, who was diagnosed with osteoarthritis (OA) five years ago.

In hospital I was too proud to ask for help

Such is the pressure on men not to show weakness that they can be injuriously stubborn. 'I was in hospital after an operation, and I broke my tooth trying to remove the lid from a marker pen, because I was too proud to ask for help,' admits Gordon Blyth, who was in his late twenties when he was diagnosed with rheumatoid arthritis (RA).

Perceptions of womanhood and femininity have become varied and complex. We've moved away from the doting housewife, with no financial or social independence being the norm. The last 50 years have seen feminism, post-feminism,

and even neo-feminism – no wonder we're confused. The 21st century woman is expected to have it all – career, family, comfortable income and a washboard stomach.

The 'fairer sex' identity dictates messages about the importance of looking pretty and attractive. Glossy magazines present very powerful, established but restrictive images of women. 'I'd be lying if I said I never think that I'd like to be a size 10,' says Homaira Khan, who has RA. 'But I think that by buying these magazines you buy into that image of women. I get frustrated when people see my disability. I want them to look at me being a woman, not for being disabled.'

These pressures to conform are particularly acute during adolescence. 'When you're a teenager you just want to be the same as everyone else,' says Philippa Jones, who has RA.

'I was a teenager in the 70s. My rheumatologist said that platform shoes were ok, as long as they weren't too high. He was great, because I think he appreciated that body image and social inclusion were as much a part of managing my arthritis as physical things.'

By its nature, fashion changes. 'Unfortunately, comfortable is rarely fashionable, especially where shoes are concerned,' says Liz Mines, who was 26 when she was diagnosed with arthritis. Homaira supports this view: 'I find it hard to buy nice clothes. I don't want to feel like a frump, I want to dress for my age,' she says.

Feeling fashionable when you have arthritis is a question of manageability. Eileen Stebbings, from Hull, takes a practical approach to her appearance, keeping her hair short and permed so she doesn't have to think about blowdrying or brushing it.

Clothes have to be convenient too: 'I have problems with trousers. I sometimes have to wear a brace on my knee, which I want to cover up, so I wear trousers, but they are harder to put on,' she says. 'Skirts are easier if I am having a bad day.'

Some people get despondent after being diagnosed with arthritis, and stop caring about their appearance. That said, other people respond to

diagnosis by taking greater care of themselves, feeling that they may have had to relinquish power and independence to their condition, but they aren't going to let it lick them. Pampering yourself is a great way to relax, and an indulgent distraction technique, whether it's a facial, having a long soak in the bath, or watching the football.

Medication for treating arthritis, particularly steroids, can cause physical side effects, including weight gain. This can be genuinely distressing, as Homaira can testify: 'I would go to family parties and be told, in front of a large group of people, "Homaira you've put on a lot of weight." I felt like I had to justify myself, but what can you say, especially when that person may not even know you well, and may not even know that you have arthritis.'

However, Homaira notes that disability has really put things in perspective for her. 'Going through all the emotions of dealing with having arthritis has by no means been easy, but it has given me confidence, a sense of humour and optimism. These are all much more mature ways to define the self.'

Unfortunately, comfortable is rarely fashionable

Not being able to work, or having to rely on a partner for more traditionally 'male' things, such as providing for your family, can present huge acceptance issues for men. Admitting to having limitations, or to not being able to do what was once easy, is very frustrating.

'You can feel a sense of grief and resentment as your capacities disappear, and as your pleasures become curtailed,' says Phillip Hodson. This is particularly common amongst men, whose hobbies and interests tend to be more physically active.

'I think men's identity is very much defined by economic prowess,' says James Ashmore, who is a self-employed headhunter. 'For a long time I was the breadwinner, but having

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arthritis meant I couldn't go out and earn as I had been doing previously. My wife has gone back to work after 18 years – which she's enjoying enormously. Arthritis robbed me of my energy and vigour, which are to me important aspects of masculinity, but now I've had surgery on my hip – which has improved my mobility massively – I feel as if I've got my life back.'

These days women, too, define themselves by work. Homaira was diagnosed with RA when she was 23, just as her career was taking off. 'I was young, free and single. I was earning money, which I could spend however I liked,' she remembers. 'Being diagnosed with arthritis was absolutely devastating. I looked at my female friends and saw them getting promoted, and there I was, sitting at home.'

It is important to keep going with as much as you can, but to make sure that you are not pushing yourself excessively. Gordon has osteoarthritis in both knees and has had to give up two of his passions in life, mountaineering and angling, as a result. He still tries to do as much DIY as possible. 'If your tools are sharp you don't need to put in the same amount of elbow grease. It's lifting that I have the most problems with,' he says.

If your confidence is affected by your arthritis, this can affect how desirable you feel too. People with arthritis can be reticent in talking about their condition with a new partner, for fear of giving a negative impression. 'Arthritis is just not sexy and cool,' says Phillipa.

'When I was 17, I told a boyfriend that I had water on my knee when I went to have it drained, because I thought that sounded more glamorous.'

Dr Tuppy Owen, founder of Understanding Outsiders, an organisation that supports personal and sexual relationships for disabled people, feels that

disabled men have to challenge their ideas about strength and masculinity, and women need to challenge their ideas about how they understand 'womanhood'.

'It's basically about confidence,' she says. 'Sadly we only have a few members who are under 25. Most people have waited around, often being very unhappy, before they have done anything about trying to find a partner.'

People sometimes invite a lot of self-criticism and judgement. 'You are a woman, even if you can't perform all the postures in the karma sutra, and you are a man, even if you can't operate a powersaw,' says Phillip Hodson.

'That said, physical impairments can present practical issues with sex, and when the process becomes a chore rather than a pleasure it can be offputting,' Philip adds. It is important not to ignore these, but to talk them through. You may be able to find comfortable positions that work for both of you.

I can still be beautiful and have scars

Some women can be anxious about the future, settling down and starting a family. 'I became aware of it when friends, especially those who are younger than me, started getting married. I thought a lot about settling down, and what that might mean,' says Homaira.

'I thought I'd be a burden. I asked myself who would want to be with someone who has so many health problems.' However, Homaira married a year ago, and says her husband tells her he forgets she has arthritis. 'He doesn't define me by my condition, which is refreshing and I know I can still be beautiful and have scars.'

Arthritis can also affect decisions around parenthood – a road down which the burden of roles and responsibilities are heavy for men and women. Having arthritis can mean having to suspend medication whilst trying to conceive, or for the duration of the pregnancy, and then managing the demanding long-term responsibility of having a child, with a demanding long-term condition.

'I had just had my first son, when I was first diagnosed. Then I went into remission, during which time I had two more children, and then I became ill again a few years later,' says Liz. 'I had problems changing them, feeding them, picking them up. Yes, I did find it very difficult,

but I had daily responsibilities and I just had to get on and do them.'

Eileen Stebbings was diagnosed with osteoarthritis in between having her two children. 'I think the parental instinct is very powerful, and can over-ride pain. You're so busy worrying about your children that the last person you think about is yourself,' she says. It can be a good distraction technique, but not taking care of yourself also poses the risk of injury, exhaustion or flare-ups. Lots of men and women in fact make the decision not to have children because they consider the demands of raising a family conflict too much with the demands of their condition.

Challenging established perceptions of gender can be liberating. 'Disability gives you insights. You learn to look at the world in a more generous way, rather than that of an impatient child,' observes Phillip Hodson. 'Women learn what it is to have power taken away and resolve not to have the rest taken away. By the same token, men who might have assumed they would always be powerful have to cope with losing their power, and learn to appreciate other people more.'

Gordon Blyth agrees: 'I am absolutely convinced that having arthritis has made me more empathetic, and better able to express my emotion. It has helped me a great deal, in relationships in my life, not just in relation to my arthritis.'

Philip believes as people gain wisdom and maturity, they have more choices available: 'You can think "I'd rather not have arthritis, but I do, and I can choose to be a woman (or a man) who is sexy and desirable, if you're lucky enough to get to know me".'

There's some irony in that although arthritis can dent your confidence, learning to live with it can actually give you more confidence. It is all about feeling comfortable in your own skin. 

