

Resource

## Foot health case studies/patient stories

Foot problems can have a huge impact on life for people with RA. Here, people share their stories of how they have coped with their foot health and the impact that foot problems has had on their lives.

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My foot and ankle journey so far with RA by Ailsa Bosworth



Feet and footwear really can be the bane of life for many people living with RA. In my experience, it is people with longer-standing disease who are likely to have more problems with their feet as, thankfully, those diagnosed within recent years have had access to better, more aggressive treatment and, of course, access to biologic therapies if standard treatments fail. The revolutionary change in the way in which this disease is now treated by comparison to when I was diagnosed more than 30 years ago, means that less people are likely to sustain irreversible damage because of inadequate treatment, and many more will be able to lead normal lives.

However, back to my feet .... I honestly can't now remember when I stopped being able to wear normal shoes and, oh my goodness – heels! I think it was around '89/'90 that the damage, particularly in my left ankle joint started to cause me real problems. My ankle had what is called a 'valgus drift' which means the ankle was out of alignment and bending in towards my other ankle, which you can see in the photo.

This meant that any shoe I was able to get on gaped in a very unattractive way. I have narrow feet, and so all the various shoes like Ecco and Hotter didn't fit properly. I can remember my husband, and I spent ages going round various shoe shops and always coming home disappointed. The result was that for many many years, all I wore were clogs like the ones pictured above, which gave me cushioning and were at least comfortable, although the pain I experienced was frequently very debilitating. Even in winter and when it was pouring with rain, I would still be wearing my open-toed clogs. The anguish it caused when going to a social event when I was all dressed up and with nothing to wear on my feet will be familiar to many reading this, I am sure.

Going to my God-daughter's wedding, I could find nothing other than a pair of slip-on Clark's sandals which I still wear around the house today, and so felt that everybody would be looking at my feet (which of course they weren't but one doesn't think rationally about these things at times!)

All dressed up and rubbish shoes!



My ankle became so painful that I underwent a triple arthrodesis operation in the late nineties, which fused my ankle & foot by putting a screw through the sub-taylor joint, which is below the ankle joint. This was the first of four operations to my feet and ankles which necessitated a recovery period of about 12 weeks of which about 10 were non-weight bearing. The post-operative difficulties that being non-weight bearing causes are huge, especially if you can't hop around on crutches which I can't having had both elbows replaced. We had a stairlift installed which I use daily as going up and downstairs is not the easiest thing, and of course, when my leg was in plaster or in an airboot it would have been impossible, so this was a lifesaver. I basically spent 3 months confined to the upstairs. I transferred my office to a spare bedroom and worked from there. Thank goodness for modern communications, being able to work whilst immobilized saved my sanity.

The operation took some of the pain away and made things more bearable for a while, but within a year or two I had to have the ankle replaced on that foot and subsequently on my right foot. These operations had managed to straighten the valgus drift a bit which meant I could get lace-up type shoes on which did make a positive difference to the types of shoes I could wear. I particularly found that Rieker shoes (see below) were good and fitted my feet quite well and you can get them in different colours which gave a bit of flexibility with clothes.



A year and a half ago, I suddenly started having extreme pain on weight-bearing and went to my GP who initially thought it might be cellulitis and gave me anti-biotics. This did nothing at all, and so I got an emergency appointment with my consultant, who immediately x-rayed my ankle and sent me to see his ankle surgeon the same day. His advice was to see my own ankle surgeon who had done all the previous surgery immediately. Within 2 weeks, I was in hospital and undergoing the third operation to my left foot/ankle. He replaced the plastic spacer between the ankle joint prosthesis with a bigger one and managed to straighten my ankle even more as a result.

The operation was successful although an open wound on my heel where they put the screw back in (see x-ray below) meant that I had to stay off my drugs for 12 weeks by which time I could hardly move and was in agony. This really brought home to me how dependent I am on my Anti-TNF.



During these operations, I have had various toes straightened, although two are still out of alignment I am now able to walk better, further and stand up for longer and I can wear normal shoes of a particular type which makes me feel SO much better. I still get pain on a daily basis, and I can now feel one of the metatarsal heads in the middle of my left foot, sometimes feels a bit like standing on a marble, so that will no doubt be the next thing, but I can continue to work, and I don't need to use the wheelchair as much as I did before the last operation.

I am immensely grateful to my wonderful foot surgeon whose skill has enabled me to get on with my life, but I am acutely conscious of just how important it is to have good, expert foot care and to get surgical advice at an early stage so that should surgery be necessary, the surgeon has something to work with, and you are likely to get better outcomes than waiting till it is too late and a good outcome is less likely.

Things which haven't worked well for me are custom-built insoles, although I know that these can be very beneficial for many. On two occasions, I have had custom-built insoles which I have found so uncomfortable that I couldn't wear them. Part of the problem was that I was simply sent them through the post by the podiatry department, even after they were modified the last time, but I still could not get them into my shoes very well without the depth of the insole pushing my feet out of my shoe and due to my collapsed arches, (they were 2/3rds insoles) they were just too painful. I also had a pair of shoes made some years ago, which I have never worn because they just weren't right or comfortable.

In my job, I can't wear trainers as I have to look business smart most of the time and over the years I have had to change my wardrobe completely, and I only wear trousers and long skirts. I would so love to be able to wear a knee-length outfit but with problem feet, unsuitable shoes and scarred knees, I just wouldn't feel comfortable. However, I am in a better place today than I was years ago with my feet and am grateful that I can now at least wear 'normal' shoes. I still gaze longingly at Jimmy Choos and other beautiful shoes when I pass shoe shops, but they're for wearing in my dreams!

## Feet! By Marion Adler

Having been diagnosed since 1995, I have always been puzzled and sometimes infuriated by the relative neglect of foot problems caused by RA since I – like many others – suffered very early on from RA in my feet – have now had surgery on both, with limited success, and may need more surgery shortly. The omission of feet from the DAS scoring has always been baffling to me.

My RA is fairly quiet now, but the damage it did to my feet has left me unable to walk far or stand still without pain.

Footwear:

If you have painful feet, you have to get to become an expert shopper and possibly resign yourself to a much more limited range of footwear than you would wish. These are my suggestions :

- use the internet – there are masses of online shoe shops
- use google keywords – ‘wide feet’ or ‘comfort shoes’ or anything else that describes your needs – and search widely
- try as many brands out as you wish – don’t just go for one that someone recommended
- buy shoes online. You can try them at home at different times of the day, or on good/bad days and have a reasonable time to return them if not suitable – if you do buy something in a shop, check their returns policy to give you time to try at home – or leave the shop, and find the ones you want online
- look for lightweight footwear
- look for flexible footwear
- look for soft materials/leathers
- look for shoes without stitching over sore places, if you know where these are!
- look for insoles in shoes that soften the impact, or use insoles of your own – these vary a lot and need to be right for you – podiatrists can make these for you on the NHS or can be widely bought. Podiatrists can also help with pressure spots pain from otherwise generally comfortable shoes
- look for footwear that supports your feet adequately, and which is adjustable as foot pain varies from day to day
- trainers can be excellent, and not too pricey
- if you find something really great, buy another pair before they stop making them
- no two pairs of shoes that you wear are the same – try changing halfway through the day if your feet are having a bad day
- be prepared to spend more on shoes than you might have once done!

## Zelia’s story

My name is Zelia, and I am 80 years old. I was diagnosed with RA when I was 59. It all started with a painful left big toe. At that time, I was a full-time nurse, and I found that the sole of my feet began to be very painful, especially when walking. The right foot deteriorated to such an extent that it caused a callous on both feet which, unfortunately, ulcerated on the right sole.



Over a period of time, walking became very difficult. My specialist in Sheffield suggested I had an operation on my feet to remove the callous and thus make walking a lot easier.

In June 2000, I went into hospital for a Bilateral Forefoot Arthroplasty. The operation went extremely well and was able to walk without as much pain and unaided.

Without this operation, I feel I would have been immobile and struggling to do the simplest of tasks such as climbing stairs and playing with my grandchildren.

I know that at present, there is not a cure for RA. However, with the dedication of the medical teams, I have now transferred to the excellent facilities at Lincoln, especially the consultants, specialist nurses and the research into new medications. RA is, for me, controllable. The anti-TNF treatment I now take has certainly made my life that much easier.

From contributors to our HealthUnlocked forum:

I had my toes straightened a few years ago. For years before that, I could only wear trainers, so it impacted my social life – you can't look dressed up with trainers. I had almost stopped going out to anywhere where I could not wear jeans.

Now I can wear any of the lovely flat shoes around, so I am now able to wear dresses and skirts again. I feel like a new person, and I now have a busy social life again.

I would certainly recommend having it done; for me, it was 'lifestyle-changing'. I have had toes on both feet done at different times.

No problems at all, even with the second op where, because I had no pain and only discomfort for a couple of days after the op, I kept forgetting to wear the special sandal which they give you.

I don't have any pain in them now, and of course, I can wear fashionable shoes again.

My consultant said I may have to have them redone because of the RA, but they haven't bent again yet, and it is 3/4 years since I had them done.

As with any op, there could be problems, but I would certainly have it done especially if you are in pain. The only downside for me is that I have lost some sensation under my toes but to be honest, that is not really a problem.

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