

A CALL TO ACTION

Providing better footwear and foot orthoses
for people with rheumatoid arthritis



**'MORE AND MORE I BELIEVE
THERAPEUTIC PARTNERSHIP
IS THE CENTRAL KEY TO BEST
PRACTICE AND CARE. GOOD
RELATIONSHIPS WILL ALMOST
ALWAYS END SUCCESSFULLY, EVEN
WITH PROBLEMS OF RATIONING,
SERVICE SHORTAGES AND
UNDERFUNDING ETC. PATIENTS
WILL NEVER BE DISAPPOINTED
IF THEY FEEL SOMEONE HAS
DONE THEIR VERY BEST'**

EXECUTIVE SUMMARY

Without good quality therapeutic footwear people with rheumatoid arthritis are often left unable to walk, and the condition of their feet degenerates.

Rheumatoid arthritis is a chronic, disabling condition in which the body's immune system attacks the joints. As the disease progresses, feet become more damaged and deformed.

Research produced for this report shows widespread dissatisfaction with all types of therapeutic footwear, and patients have raised concerns around poor fit, appearance, weight of shoe and comfort.

- Nine out of ten rheumatoid arthritis patients complain of foot pain
- Seven out of ten having difficulty walking
- Eighty per cent report problems with their footwear.
- High street and therapeutic footwear designers and manufacturers do not fully embrace the therapeutic needs of the patient. These factors have an impact on patient quality of life and well-being.

The report makes a series of observations and recommendations for the current service, which has been failing for the past two decades to provide accessible podiatric and orthotic services at a time of growing demand from an ageing population.

- Health care professionals routinely fail to understand the needs of patients, resulting in shoes being made that people will not wear which could lead to further deterioration and greater health problems.
- There should be a system overhaul and improved training of podiatrists, orthotists and primary care specialists to ensure the effective provision of appropriately designed footwear to meet the needs of people with rheumatoid arthritis.
- High street opticians provide a good example of what orthotic provision could be like, with patients choosing shoes within the framework of a prescription that addresses their therapeutic needs

INTRODUCTION

'Assistive technology services (including orthotics) are the gateway to independence, dignity and self-esteem.' – The Audit Commission, 2000.

'I couldn't get out...I just couldn't get anywhere...to get up and down the stairs was with great effort...up until then I was working practically full time so obviously I was off sick, my world had suddenly shrunk'

– Rheumatoid arthritis sufferer, 2011.

Around 400,000 adults suffer from rheumatoid arthritis (RA), the most common form of inflammatory arthritis, with 20,000 new cases being diagnosed every year¹. The disease is characterised by inflammation of the synovial tissue responsible for maintaining the nutrition and lubrication of the joints. This can cause pain and swelling and, if left untreated, leads to permanent structural damage to the bone and eventual long-term disability.

While the impact of rheumatoid arthritis is distributed through all synovial joints, the impact on the feet is significant. Foot pain, even to a mild degree, is a significant marker for impaired social mobility, functional incapacity and psychosocial health². Almost all people with rheumatoid arthritis have some degree of foot involvement³, with the MTP (metatarsophalangeal) joints in the foot showing damage more often and earlier than the equivalent joints of the hand⁴. While there is a lack of good epidemiological data charting the disease progression in the foot, it is generally accepted that prevalence of foot deformities increases with advancing duration of the disease and age.

Seven out of 10 patients report pain and swelling in at least one foot at diagnosis, decreasing to between 40–50 per cent after 2 years following treatment with disease-modifying anti-rheumatic drugs⁵. There is emerging evidence that many patients with rheumatoid arthritis are left with residual foot impairments even when disease activity has been suppressed by drug therapy. Nine out of 10 rheumatoid arthritis patients complain of foot pain during the course of their disease⁶, with eight out of 10 reporting current problems and more than seven out of 10 reporting difficulty in walking due to problems with their feet⁷.

Yet when disease control is good, there is evidence that addressing the mechanical causes of foot problems before changes in the feet become well developed can have significant benefit⁸. Poor footwear is a major contributing factor to foot problems for people throughout the rheumatoid arthritis journey, while therapeutic footwear and foot orthoses are of proven benefit to people with the condition, with the potential to alleviate pain and increase mobility and independence. Indeed, the evidence shows that for every £1 spent on orthotic services, the NHS can potentially save £4⁹.

1 Symmons DPM et al. The incidence of rheumatoid arthritis in the United Kingdom: results from the Norfolk Arthritis Register. *British Journal of Rheumatology* 1994; 33: 735–39.

2 Wickman A. Health-related quality of life for patients with rheumatoid arthritis foot involvement. *Foot & Ankle International* 2004; 25: 19–26.

3 Farrow S et al. Interventions for foot disease in rheumatoid arthritis: A systematic review. *Arthritis and Rheumatism* 2005; 53: 4, 593–602.

4 Lindqvist E et al. Course of radiographic damage over 10 years in a cohort with early rheumatoid arthritis. *Annals of Rheumatic Diseases* 2003; 62: 611–16.

5 van der Leeden M et al. Prevalence and course of forefoot impairments and walking disability in the first eight years of rheumatoid arthritis. *Arthritis & Rheumatism*. 2008; 59(11): 1596–1602.

6 Minaker K, Little H. Painful feet in rheumatoid arthritis. *Canadian Medical Association Journal* 1973; 109: 724–30.

7 Grondal L et al. The foot: still the most important reason for walking incapacity in rheumatoid arthritis. *Acta Orthopaedica*. 2008; 79(2): 257–61.

8 Woodburn J et al. A randomized controlled trial of foot orthoses in rheumatoid arthritis. *The Journal of Rheumatology*. 2002; 29(7): 1377–83.

9 Boxer P, Flynn T. Orthotic Pathfinder: A patient-focused strategy and proven implementation plan to improve and expand access to orthotic care services and transform the quality of care delivered. *Business Solutions*. http://rslsteeper.com/uploads/files/281/orthotic_pathfinder_report_july_2004.pdf

The cost effectiveness of good orthotic and footwear services is recognised by the National Institute for Health and Clinical Evidence (NICE)¹⁰, which recommends the following:

- All people with rheumatoid arthritis and foot problems should have access to a podiatrist for assessment and periodic review of their foot health needs.
- Functional insoles and therapeutic footwear should be available for all people with rheumatoid arthritis if indicated.

Yet a series of reports over the last two decades has profiled a continuing failure to provide well-organised, accessible podiatric and orthotic services at a time of growing demand from an ageing population, as well as a dearth of high-quality prescription footwear that combine clinical effectiveness with style and comfort.

In 1992, a highly critical report for the Department of Health by Professor Peter Bowker of Salford University warned that: 'NHS Orthotics services are rudderless... with...informed management, service audit and strategic planning [having] little place'¹¹.

Eight years later in 2000, the Audit Commission, reporting on the provision of equipment to older and disabled people, including footwear and orthotics provision, warned of 'unexplained variations in all aspects of assistive technology provision with little relation to underlying need'¹². It also highlighted the poor levels of design endemic in the disability equipment sector, citing this as one of the reasons why so many products remained unused.

A further report by the Audit Commission in 2002 reported the failure of orthotics to improve its service¹³. And in 2004, the Department of Health's Orthotic Pathfinder study described NHS orthotic services as 'a primary care-led service, buried in the acute care system' and as such, 'a poor relation in healthcare delivery'¹⁴. It warned that patients do not receive appropriate orthotic care at the right time, with many patients who could have been stabilised by orthotists suffering serious loss of mobility. In particular, it warned that the elderly are more likely to lose mobility and often end up requiring more acute intervention as a result, including hip replacements and treatment for falls.

The EFFORT project (Exploration of Footwear and Foot Orthoses in Rheumatology Treatment), consisting of an in-depth qualitative and quantitative study and online surveys, commissioned by Arthritis Research UK and summarised in this paper, brings these concerns up to date. Sadly, it provides evidence that the provision of footwear remains one of the least satisfactory aspects of the overall care of people with rheumatoid arthritis.

A central finding is that 20 years after the Bowker report, only one in 10 respondents are satisfied with the currently available range of shoes. Nine out of 10 respondents who have been prescribed shoes are concerned about their appearance and feel they have to change the clothes they wear to accommodate or hide the shoes. The study also showed that service users resorted to buying shoes privately, choosing wide-fitting shoes made of a supportive material such as leather. Eight out of 10 respondents who replied had problems with their shoes, with fewer than half of respondents finding their insoles a useful aid to their mobility.

10 National Institute for Health and Clinical Excellence. Rheumatoid arthritis: the management of rheumatoid arthritis in adults. www.nice.org.uk/CG79

11 Bowker P et al. A study of the organisation of the orthotic services in England and Wales. - London: Department of Health (1992).

12 Audit Commission (2000). Fully equipped: the provision of equipment to older and disabled people by NHS Trust and Social Services Departments in England and Wales. - London: Audit Commission

13 Audit Commission, Assisting Independence - Fully Equipped 2002.

Available at: <http://www.audit-commission.gov.uk/SiteCollectionDocuments/AuditCommissionReports/NationalStudies/upequip02.pdf>

14 Boxer P, Flynn T. Orthotic Pathfinder: A patient focused strategy and proven implementation plan to improve and expand access to orthotic care services and transform the quality of care delivered. Business Solutions. Available at: http://www.rslsteeper.com/upload/files/105/Orthotic_Pathfinder_Report_July_2004.pdf

As this project makes clear, it is not only NHS organisational practices that are stuck in the past. The orthotics and therapeutic footwear industry also remains bound by obsolete models of manufacture and technology, appearing to assume that design and aesthetics are not important in remedial footwear.

Some good news does exist in the form of examples of good practice in trusts that have improved access to and management of orthotic services as well as raising the quality of footwear. A potentially workable model may mirror modern high street optometry with its focus on patient choice and the opportunity for spectacle wearers to trade off their own specific needs against the relative therapeutic, aesthetic and cost implications of lens thickness, frame style and durability. It seems possible that people with rheumatoid arthritis-related foot problems could make similar choices regarding style, fastening and colour within the framework of a prescription that addresses their therapeutic need.

There may be no one-size-fits-all model because local services require local solutions. But this report suggests that existing models can be adapted so that good practice is promoted and embraced throughout the service. The recommendations on how orthotic and footwear services can and should be reconfigured to better meet the needs of people with rheumatoid arthritis have the support of the people involved in writing this report.

1. FOOTWEAR AND ORTHOSES – WHAT IS AVAILABLE FOR PEOPLE WITH RHEUMATOID ARTHRITIS?

'... some of the shoes that are churned out from these companies for people with arthritis, you feel bad enough as it is, so you certainly don't want to wear shoes like that, so I think there's definitely a market for it. I think that's why I'm even happier to take part in your study as well cos I think there must be some shoe designers out there who can make decent shoes...' – Service user

'You don't feel like walking anywhere or doing anything, all you want to do is sit down somewhere, which ruins your life to quite a big degree'

– Service user

By slightly altering the angles at which the foot contacts the floor, foot orthoses can correct an abnormal or irregular walking pattern, making standing, walking and running more comfortable and efficient. Further, by preventing misalignments of the foot, they can significantly alter the way in which the bones move with the joints, thereby improving function, reducing pain and to some degree slowing down the damage to local joints caused by the disease.

Foot orthoses that can be accommodated in appropriate footwear are the cornerstone of management of rheumatoid arthritis-related foot problems. A disease-staged approach to management with orthoses and footwear is increasingly advocated, tailoring the approach to the specific and varying requirements of the patient, although the evidence base is robust only for custom-made shoes and orthoses¹⁵. It should be recognised, however, that footwear designed to accommodate orthoses can also be a public marker for disability and can produce considerable stigma¹⁶.

Here is a brief summary of what's currently available for people with rheumatoid-related foot problems:

I. STANDARD HIGH-STREET FOOTWEAR

In the early stages of rheumatoid arthritis, swelling in at least one foot joint is common, although the foot retains its original shape. The aim should be to preserve and maintain function and to prevent and lessen deformity – something that standard high-street footwear (with or without an orthosis) can normally achieve. However, health education by service providers should help patients understand that their feet are likely to be affected by their ongoing arthritis and can be permanently damaged by wearing unsuitable shoes.

¹⁵ National Institute for Health and Clinical Excellence. Rheumatoid arthritis: the management of rheumatoid arthritis in adults. www.nice.org.uk/CG79

¹⁶ Van Der Leeden M et al. Forefoot disease activity in rheumatoid arthritis patients in remission, results of a cohort study. *Arthritis Care & Research*.2008; 59: 11, 1596–1602.

The modern high-street retail footwear industry has a number of ranges of innovative, technologically advanced and affordable footwear that can help maintain foot function and foot health. However, small changes in the design of high-street footwear could increase the choice for people who need orthoses without making these shoes inappropriate for mainstream customers.

There are also niche companies that offer specialist high-street footwear with design features such as extra depth and extra width to accommodate prefabricated foot orthoses. These include simple cushioning insoles, arch supports and other padded insoles – which, according to NICE, are suitable for general use. Many of these companies have an online as well as a high-street presence.

II. THERAPEUTIC FOOTWEAR

In more established rheumatoid arthritis, joint damage and deformity accumulate while function deteriorates. At this point, prefabricated or custom-made orthoses should be used with appropriate footwear with the aim of reducing pain, maintaining function, accommodating deformity and preventing further deterioration while maintaining tissue viability. Optimising foot function in this way has the potential to positively influence the biomechanics at the knee and hip joints as well as improve foot health. There is good evidence from NICE to support the use of heat-mouldable shoes and custom-made orthoses for this group.

THERAPEUTIC FOOTWEAR APPROPRIATE FOR THIS PURPOSE INCLUDES:

Stock shoes that have extra depth or width across the forefoot so that they can accommodate prefabricated or custom-made foot orthoses and any changes to the geometry of the forefoot; they are available with a range of fastenings and a heel or sole unit that can be modified to improve individual functionality or comfort

modular shoes that have a stock base but can be customised to individual needs and are also available with a range of fastenings and a heel or sole unit that can be modified to improve individual functionality or comfort; bespoke or made-to-measure footwear which is made on a unique cast constructed to reflect the patient's feet in order to accommodate significant deformity or to redistribute the load where mechanical function is severely compromised.

Therapeutic footwear can be provided by any healthcare professional who is trained to measure and fit these types of shoe. A limited range of stock and modular styles are available from companies that offer shoes with different fundamental features while bespoke are completely customised. However, there is widespread dissatisfaction with all types of therapeutic footwear in terms of poor fit, aesthetic acceptability, weight of the shoe and perception of comfort. There is robust evidence that the level of dissatisfaction results in poor compliance^{17,18}.

17 Callahan LF. The burden of rheumatoid arthritis. *The Journal of Rheumatology* 1998; 25 (suppl 53): 8–12

18 Symmons DPM et al. The incidence of rheumatoid arthritis in the United Kingdom: results from the Norfolk Arthritis Register. *British Journal of Rheumatology* 1994; 33: 735–39

Good practice: How a multidisciplinary footwear clinic improved patient choice, services *And* footwear

In 1998, Salford Royal Hospitals NHS Trust set up an orthotic/footwear service within the podiatry department with the orthotist working alongside podiatrists.

This change in service delivery brought about changes at a strategic level. Three sessions of the orthotist's time were redeployed to the podiatry department. All patients referred for therapeutic footwear by their consultants (mainly rheumatologists, orthopaedic consultants and diabetologists) were assessed for their need for footwear by a podiatrist specialising in footwear and foot orthoses.

Patients were then selected to see the orthotist if their clinical need required specialist footwear, provided they were in full agreement with this option.

Fifty per cent of the patients referred for specialist footwear by consultants were assessed and referred for suitable retail footwear. This decision was based on clinical need and/or the potential lack of compliance with the footwear due to its appearance.

The quality of the footwear from the company contracted by the NHS was improved following advice and monitoring by the podiatry team.

Patients led the decision making once they had been provided with the options for their foot health needs.

As evaluated through an audit, the patient usage of the footwear improved, and the patients reported more satisfaction with the service and the footwear compared with the traditional service. As footwear was demonstrated to be a successful intervention, it was replaced when worn out.

Cost savings could not be identified as the patients who were provided with the footwear achieved good clinical outcomes and wore them for the majority of the time, hence they needed repairing and replacing more frequently. However, this was deemed to be a more efficient use of the budget, resulting in improved outcomes and satisfaction for the patients. This model has been adopted in other localities (Bolton Primary Care Trust (PCT), Bradford & Airedale PCT, Tower Hamlets PCT, Northampton General Hospital and Airedale General Hospital).

2. EFFORT – EXAMINING PATIENT AND HEALTHCARE PROFESSIONAL EXPERIENCES OF RHEUMATOLOGICAL FOOT HEALTHCARE PROVISION

Two recent studies have for the first time investigated existing service provision throughout the country from the perspective of both patients and practitioners. The EFFORT project was carried out in two phases:

EFFORT 1, a qualitative assessment of the experiences of foot health interventions in patients with rheumatoid arthritis, from the viewpoints of a representative group of service users referred during the previous 2 years and service providers including orthotists and podiatrists. It involved 20 semi-structured interviews including 11 with groups of service users and nine with groups of service providers.

EFFORT 2 involved questionnaires posted on the websites of the National Rheumatoid Arthritis Society and Arthritis Research UK, and involved 113 service users and 186 health professionals including occupational therapists and physiotherapists as well as orthotists and podiatrists.

The project found that people living with this long-term, unpredictable condition valued easy access to effective and responsive health provision that meets their needs as a vital part of the overall disease management. It provided experiential evidence, summarised below, as to the extent to which these expectations are being met.

I. ACCESS TO SERVICES

'Generally it's quite difficult to access services quickly. I [as an occupational therapist] was trying to refer regularly but was told that funding was not in place for the podiatrists to be able to respond to the volume of referrals, therefore patients were redirected to the community where they didn't seem to be a priority or they have to pay for services/devices.'

– Service provider

'When the orthotist is in for half a day a week it's not surprising that it's three months before you see them for your initial appointment.'

– Service user

'I can't directly talk to the orthopaedic foot department – it has to go back via GPs so that's another waste of time and frustration from my part and obviously the patient.'

– Service provider

'The orthotist I see does try but comes to the hospital one day a week and trying to get an appointment is a nightmare.'

– Service user

'I think you pay about £70 to go and see him but it's like the convenience of being able to go after work, not miss time off work, the follow-up service, the fact that he's interested... I think even when I'm not working that's going to be one of the last things I'm going to have to let go...it is really is worth it' – Service user accessing private healthcare

Access to an orthotist or podiatrist is often inconsistent with referral pathways, unclear and subject to frequent delays. Two out of three respondents had to self-refer back to the service if there was a problem – and when this occurred, they had to follow the same pathway of going back to their GP or rheumatologist and asking for a follow-up appointment. Most said this was unsatisfactory and expressed concerns about the need to be proactive to access services.

The interviews revealed a high level of resourcefulness among service users. Strategies included buying footwear themselves and paying for a private podiatry service as well as carrying a spare pair of comfortable shoes to change into during the day.

Service users described feelings of anger, depression and grief associated with how their lives had changed – an emotional impact that had a detrimental effect on their ability to cope. Long waiting times for appointments brought an additional psychological impact as well as causing concern that this might compromise the efficacy of treatment.

Good practice: Gatekeeper practitioners provide single point of contact streamline referrals

In 2004–05 NHS Wales reformed footwear and orthotics services, introducing a gatekeeper system with a single point of contact identified as coordinating footwear and orthosis provision within each Health Board. This gatekeeper practitioner/manager coordinates referrals as well as managing the contracts with external suppliers.

An all-Wales orthotic managers' group coordinates activities and reduces unwarranted variation while local needs can still be addressed in ways that suit local circumstances. An all-Wales contract is in place for orthotic services, while local pathways streamline referrals and ensure that referrals are appropriate and are seen within agreed times.

The appointment of a gatekeeper has allowed referrals into footwear services to come from a wider range of practitioners, including podiatrists, physiotherapists, GPs, orthotists and consultants, reducing barriers to access for patients. Patients are initially referred for assessment only and are provided with orthoses or footwear according to assessed need. Where indicated, provision of insoles or footwear is based on best use of available resources rather than professional boundaries. The range of options available includes off-the-shelf and customised insoles, and stock, modular and bespoke shoes. Examples of successful implementation of the new system include the Health Boards of Swansea/Abertawe, Cwm Taf and West Wales.

II. THE APPOINTMENT SYSTEM

'...the orthotists and podiatrists only get 20 minutes for the patient. So that's difficult to assess, treat, sit there, talk to them, you know, when you've got 11 patients in a morning.'

– Service provider

Rheumatoid arthritis is a complex disease to manage and limited available appointment time was widely seen as compromising the quality of the service delivery. The time allocated for the initial appointment was often not long enough to gather all the relevant information, and there was no possibility of flexibility because of pressures on clinic time and availability of appropriate healthcare professionals, a problem exacerbated by poorly completed referral forms.

Both service providers and users were more satisfied when there was enough time to discuss available options, provide clear explanations and educate the patient. Indeed, 62 per cent of service users felt they had had inadequate assessment of their foot health needs and 87 per cent of service providers said that in order to be empathetic, it was important to spend more than the usual allotted appointment slot with a service user.

III. THE THERAPEUTIC PARTNERSHIP

'This is so frustrating. Reliving my problems over and over again is emotionally draining; it's like facing up to it all over and over again. I just want to be pragmatic and get a solution, not have to relive the nightmare of having rheumatoid arthritis again and again.'

– Service user

'I am in a good position to comment on this as I have a lot of problems with my hands and the department for hands is in the hospital where my arthritis clinic is, and she [occupational therapist] is so in touch with what I need and has supplies to hand which I can try...Whereas with feet it is a long wait for appointments, poky room and very little after care.'

–Service user

'More and more I believe therapeutic partnership is the central key to best practice and care. Good relationships will almost always end successfully, even with problems of rationing, service shortages and underfunding etc. Patients will never be disappointed if they feel someone has done their very best.'

–Service provider

'I think all the specialties benefit from having proximity to each other because there are elements of therapy that I might be aware of but I'm not specialised in, so by working with the patient at the centre and everyone round them then the patient gets the benefit of the discussion that takes place between the professionals...but you also enhance and enrich the learning experience of each of the professionals that are round in there, so it's a patient support service and there's a professional support service.'

–Service provider

The use of a central booking system where a patient is booked into an appointment slot rather than to see a particular therapist was widely seen as unsatisfactory, resulting in service users failing to see the same therapist at each appointment. Service providers also highlighted the problems of incomplete patient records raising the chances of a service provider taking over a case without being in possession of all the information, thereby requiring service users to retell their health history.

Empathetic and effective communication was seen as the cornerstone of the therapeutic relationship. Service users were likely to regard a service favourably and use, or make better use of, the footwear provided when they felt they were being listened to and their problems were understood. Service providers acknowledged that both they and service users were more satisfied when there was enough time to discuss available options and engage in health education activities. Indeed, time constraints were seen as a major factor preventing effective communication with service users as well as with other members of the multidisciplinary team (MDT).

Service providers working in general clinics where patients with rheumatoid arthritis made up a small percentage of their caseload were more likely to report difficulties in establishing a therapeutic partnership. Both service users and service providers were also more satisfied if orthoses and footwear services were delivered within a service which has specialist rheumatology knowledge and is given within the MDT setting.

EFFORT found that the following results:

- 15 per cent of service users thought that healthcare professionals worked as a team or were in close enough proximity to each other to facilitate an efficient service.
- 30 per cent of service users were able to see the same healthcare professional on return appointments, leading to frustration with repeat assessments and lack of continuity.
- Only one in two service users felt they had been listened to by providers, while nine out of 10 of service providers felt they were adept at listening to patients and identifying their needs.

Good practice: Footwear design challenge – evidence of therapeutic and mdt partnership

The Footwear Challenge, funded by Arthritis Research UK, was an iteration of the Challenge Workshops Programme, launched in 2010 by the Royal College of Art's Helen Hamlyn Centre. This inclusive design challenge provided a mechanism whereby footwear designers, female service users, orthotists and podiatrists could work collaboratively to generate footwear design concepts grounded in the needs of women with rheumatoid arthritis. Alongside the production of new design concepts for footwear, it was possible to see how small changes in the design of mainstream shoes had the potential to enable more people to purchase mainstream shoes. This initiative demonstrated the value of therapeutic and MDT partnership in addressing service user needs.

IV. SERVICE DELIVERY AND REGIONAL VARIATION

'We usually say one pair per year but if somebody has a manual job or does a sport or has two pairs of hospital shoes then we will provide a second pair or replace them as they need, so the sort of one pair year per year has probably gone out the window a bit.'

– Service provider

Considerable variation exists in the kind of footwear that is available on the NHS. Some service providers are able to offer a wide range of shoes; others recommend suppliers for private purchases while others are unable to provide footwear. The majority (89 per cent) of service users had problems with the choice and styles of footwear, and many resorted to buying shoes privately.

Both service users and service providers reported a lack of standardisation as regards assessment of footwear and orthotics needs for people with rheumatoid arthritis, with service providers reporting that they do not have access to the same assessment equipment. In some cases, budgetary constraints compromised what service providers were able to offer, with more expensive items being less available and offered on a more ad hoc basis. This was less common in specialist services.

Forty five per cent of service providers said they supplied only one pair of foot orthoses as standard practice, though if someone had specific needs they could offer more than one pair. There was widespread concern about this restriction among service users. Only 10 per cent had been given more than one pair of orthoses at any one time, and this 'budgetary measure' was regarded as a failure to recognise that people wear several pairs of shoes which require correctly fitting orthoses.

Good practice: An integrated secondary care rheumatology footwear service

Until 1999 foot health services in Leeds, in common with most other such services in the UK, were provided by a community team comprised of generalist podiatrists, supplemented by a small hospital-based service specialising mainly in diabetes. In 2000, the hospital-based service, a Rheumatology Foot Clinic service, was introduced to deliver a service comparable with that given to diabetes patients in Leeds.

High-risk rheumatology patients, including those with open ulceration, now have access to a specialist service led by a rheumatology specialist podiatrist at Chapel Allerton Hospital. Following assessment by a podiatrist within a rheumatology outpatients setting, the service includes same-day access for footwear assessment by the orthotics department at various hospital locations around the city, dependent upon where the patient lives.

The clinic protocol for prescribing foot orthoses to patients with rheumatoid arthritis and other inflammatory diseases is based on research in the field, much of which has been conducted locally. Patients with early disease and mobile foot deformities are provided with functional devices by the rheumatology foot clinic. In cases where therapeutic footwear is required, the patients are seen by the orthotist with their orthoses. Footwear is made to accommodate both the foot and orthoses. In patients where supportive, off-loading orthoses and footwear is required, the patient is seen immediately by the orthotist to have both manufactured together. Following fitting of footwear and/or orthoses, regular follow-up of patients is undertaken, with timely access back into the service should the patient require.

V. QUALITY OF FOOTWEAR AND ORTHOSES

'Basically a complete lack of interest from 'foot people'. I feel like I'm being 'patched up' and sent on my way with no thought for ongoing problems and after care.'

– Service user

'This affects every waking moment of your life. They [the shoes] are clumsy, frumpy and depressing.'

– Service user

'I was very upset...because they're not the sort of shoes that I would normally want and these were actually the only ones that I could really get my feet in comfortably and I remember...almost crying because I was so upset, I wanted them and needed them.'

– Service user

'The service received is deplorable and I have yet to receive a pair of shoes I can actually wear. One pair actually looked and felt like two left shoes.'

– Service user

'When I go for shoes, I'll go for an extra wide fitting and I look for leather and for something that'll give me support...in that way if I'm not wearing my hospital shoes at least I'm not doing great damage to my foot.'

– Service user

Therapeutic footwear with poor aesthetic qualities can have a negative impact, creating a poor self-image. The financial burden on patients who have to pay for footwear and orthoses can be considerable – with this burden being a waste of money when, as frequently occurs, the shoes are unsuitable and not used.

EFFORT found the following results:

- 89 per cent of service users reported having problems with the choice and styles of footwear available on the NHS.
- 10 per cent were satisfied with the current available range of shoes.
- 90 per cent were concerned about the appearance of prescription footwear and found that they had to change what clothes they wore to accommodate or hide the shoes.
- 80 per cent had problems with their shoes.
- 50 per cent said the footwear was not appropriate to their needs and, where they were able, they bought their shoes privately.
- Fewer than 50 per cent said they found their insoles a useful aid to mobility.
- The therapeutic implications of this poor level of service are particularly worrying:
- 73.5 of service users were unable to carry out activities to a standard that was acceptable to them, with a similar number of those in employment finding that their foot health problems had an impact on their ability to work.
- 82 per cent of respondents were unable to engage in desired leisure activities.
- 72 per cent of respondents had resorted to simply 'hoping' for recovery.

Yet small changes to high-street ranges could increase choice dramatically. A major improvement would be the introduction of removable inner soles in dress shoes for women, similar to those that are already routinely integrated into the designs of athletic, comfort and some casual shoes. Without these removable inner soles, a foot orthosis often cannot be worn inside many shoes that can be worn with a dress or skirt.

Further, specialist footwear that is appropriate for this stage of rheumatoid arthritis tends to be expensive and difficult to access. Drives to educate both clinicians and service users about the range of products that is available, including those at the lower end of the scale, would help to bring about improvements in mobility and foot health.

As regards therapeutic footwear, major improvements in the design of the shoes themselves are also overdue. Patient involvement in the design process and throughout the process of supplying, fitting and monitoring footwear has been shown to result in new designs that improve patient satisfaction and use of the shoes as well as pain scores^{19, 20}.

VI. DELIVERY AND FOLLOW UP

'It can take up to 6 months for a new pair of shoes – my last pair took almost a year actually. During that time I had one pair of shoes to wear – so what was I supposed to do when they needed repairing?'

– Service user

'...I think personally that just putting stuff in the post and sort of saying, 'Goodbye, that's it unless you're really desperate'... almost a cheapskate way to do it because I'm sure that a lot of insoles just sit in shoes and never get used.'

– Service provider

19 Williams AE, Nester CJ, Ravey MI. Rheumatoid arthritis patients' experiences of wearing therapeutic footwear – a qualitative investigation. *BMC Musculoskeletal Disorders*. 2007; 1(8): 104.

20 Office for Health Economics Health Statistics Compendium 2001.

'Sending the insoles in the post is just an atrocious thought; I mean it's hard to think that it still goes on.'

– Service provider

'I said, 'What do I do if they're not right or...if you've got any queries?'...You can phone but they're obviously not following people up routinely.'

– Service user

'... They presented me with the orthotic there and then and never checked whether it fitted my foot properly. They didn't check my shoe; I was having problems wearing it, getting it in my shoes.'

– Service user

'I'm just fed up because it never seems to work as regards shoes...I just think if it's down in the notes and you've sent back two pairs already there must be something wrong and why haven't they taken that on board?'

– Service provider

Despite robust evidence that both a fitting appointment and the arrangement of adequate follow-up is a necessary component of the overall care package when providing footwear and orthoses ^{21, 22}, the EFFORT studies found many service users still received these through the post and failed to receive adequate follow-up. There was widespread concern that this was the case, with 67 per cent of service users and 73 per cent of service providers saying that this practice was unacceptable. In addition, 75 per cent of service users were unhappy with the length of time it took for them to receive their item.

21 Williams A, Meacher K. Shoes in the cupboard: the fate of prescribed footwear. *Prosthetics and Orthotics International* 2001; 25(1): 53–59.

22 Helliwell PS. Lessons to be learned: review of a multidisciplinary foot clinic in rheumatology. *Rheumatology*. 2003; 42(11): 1426–27.

3. RECOMMENDATIONS

I. PEOPLE WITH RHEUMATOID ARTHRITIS SHOULD BE REFERRED FOR PROMPT ASSESSMENT, MANAGEMENT AND SPECIALIST REVIEW, IN LINE WITH THE STANDARDS OF CARE FOR PEOPLE WITH MUSCULOSKELETAL FOOT HEALTH PROBLEMS, AS RECOMMENDED BY ARTHRITIS AND MUSCULOSKELETAL ALLIANCE AND THE PODIATRY RHEUMATIC CARE ASSOCIATION ²³.

Timely and equitable access to specialist foot health services should be available. Referral should include consideration for all types of insoles/footwear (retail to bespoke) as well as other options such as surgery.

II. PATIENTS SHOULD BE GIVEN REAL CHOICES AT EVERY LEVEL.

A retail-type experience is expected and possible. Fitting appointments for all insoles and footwear could facilitate improved fit, efficacy, compliance and service user satisfaction.

People requiring orthoses or footwear should be given time to consider choice but delays in provision should be minimal.

Patient and practitioner education is needed to support informed choices.

People should be allowed choice on the extent of compromise between the therapeutic and aesthetic properties of footwear.

III. EVIDENCE SHOULD INFORM AVAILABILITY OF OPTIONS.

There is moderate evidence supporting the use of some types of insole and moderate evidence for the merits of footwear. This should be incorporated into service planning.

There is a requirement for research into a number of specific applications.

Service users and providers indicated greater satisfaction if care is delivered within a service which had specialist rheumatology knowledge.

There is a need for evidence relating to the characteristics of effective footwear.

IV. SERVICES SHOULD BE CONFIGURED TO BEST ADDRESS THE NEEDS OF PEOPLE WHO USE ORTHOTIC SERVICES WITHIN A LOCAL HEALTH ECONOMY.

Formal referral and care pathways should be developed as a priority and be fully understood by all healthcare professionals involved in the management of rheumatoid arthritis. The introduction of standardised screening tools and referral forms will ensure that service providers have sufficient information about the patient prior to the appointment, with the option of setting up triage clinics to bring about even earlier access to services.

²³ www.ama.uk.net/pdfs/musculoskeletalfoothealthproblems.pdf

V. COLLABORATIVE MULTIDISCIPLINARY TEAM (MDT) WORKING SHOULD BE THE NORM, WITH THE OPPORTUNITY FOR SERVICE USERS TO BE INVOLVED IN SETTING THE AGENDA FOR CONSULTATIONS.

MDT working appears to provide a more streamlined and potentially a more economically efficient service that acknowledges the complex needs of these patients. However, regular and coordinated reviews of MDT working, along with a holistic and ongoing assessment of need, should aim to ensure that the service is preventive as well as responsive to existing disability.

VI. THE RELATIVELY SMALL NUMBER OF SERVICE USERS WHOSE FEET ARE VERY DAMAGED BY RHEUMATOID ARTHRITIS SHOULD RECEIVE A GENUINE BESPOKE SERVICE.

This should involve a therapeutic triadic relationship between the patient, the orthotist and the footwear manufacturer. There may also be a need to review the level of foot deformity that requires this intervention in order to eliminate current regional variation.

VII. STANDARD 15 OR 20-MINUTE APPOINTMENTS CREATE UNACCEPTABLE TIME PRESSURE.

There should be built-in flexibility to allow for longer appointments when needed, including allowing extra time for a comprehensive initial assessment.

VIII. THERE SHOULD BE CONSISTENCY IN ASSESSMENT AND ADEQUATE TIME TO DEVELOP A THERAPEUTIC PARTNERSHIP IN LINE WITH PATIENT EXPECTATION.

Training of service providers to adopt best clinical practices and refine their listening and health promotion skills will improve service user experience.

IX. PATIENTS NEED AND WANT FOLLOW UP.

Continuity of care for this group of people with long-term needs is highly desirable, both through seeing the same therapist where possible and as ensuring that patient records are comprehensive and complete enough to allow another healthcare professional to take over the case seamlessly.

Following provision of footwear or orthoses, patients should be seen for review within 4 weeks in order to receive evaluation for fit, comfort, effectiveness and satisfaction. Further reviews should continue to be carried out at timely intervals.

Formal health outcome evaluation should be undertaken to capture data on efficacy and cost effectiveness of interventions as well as to ensure measurable benefits to individual patients.

In order to better enable patients with rheumatoid arthritis to self-manage their foot problems, they should be provided with clear, written instructions regarding their foot health care, and how and when to contact their service provider for review of their footwear or foot orthoses.

THANKS

ARTHRITIS RESEARCH UK WISHES TO ACKNOWLEDGE THE CONTRIBUTION MADE TO THE DEVELOPMENT OF THIS REPORT BY THE MEMBERS OF THE ORTHOTICS ADVISORY GROUP (OAG):

KARYN ROSS

Chair of OAG, Orthotist, teaching fellow, National Centre for Prosthetics and Orthotics, University of Strathclyde.

DR LYNNE GOODACRE

Occupational therapist, honorary lecturer in medicine at the University of Lancaster, senior research associate at the University of East Anglia.

CLODAGH MURPHY

Service user.

DR MARGARET MCARTHUR

Occupational therapist, director of MSc pre-registration programme, School of Allied Health Professions, University of East Anglia.

DEBBIE PEEBLES

Orthotist, prosthetic/ orthotic manager, opcare limited, Cambridge.

DR ANTHONY REDMOND

Podiatrist, Arthritis Research UK senior lecturer, Leeds Institute of Molecular Medicine, University of Leeds.

PROFESSOR ALAN SILMAN

Medical director, Arthritis Research UK.

DR ELAINE THOMAS

Reader in biostatistics, Arthritis Research UK Primary Care Centre, Keele University.

DR DEBBIE TURNER

Podiatrist, Arthritis Research UK senior lecturer, Glasgow Caledonian University.

SALLY UNDERWOOD

Service user.



Providing answers today and tomorrow

Arthritis Research UK
Copeman House, St Mary's Gate
Chesterfield, S41 7TD

www.arthritisresearchuk.org

Registered Charity England and Wales No. 207711, Scotland No. SC041156.