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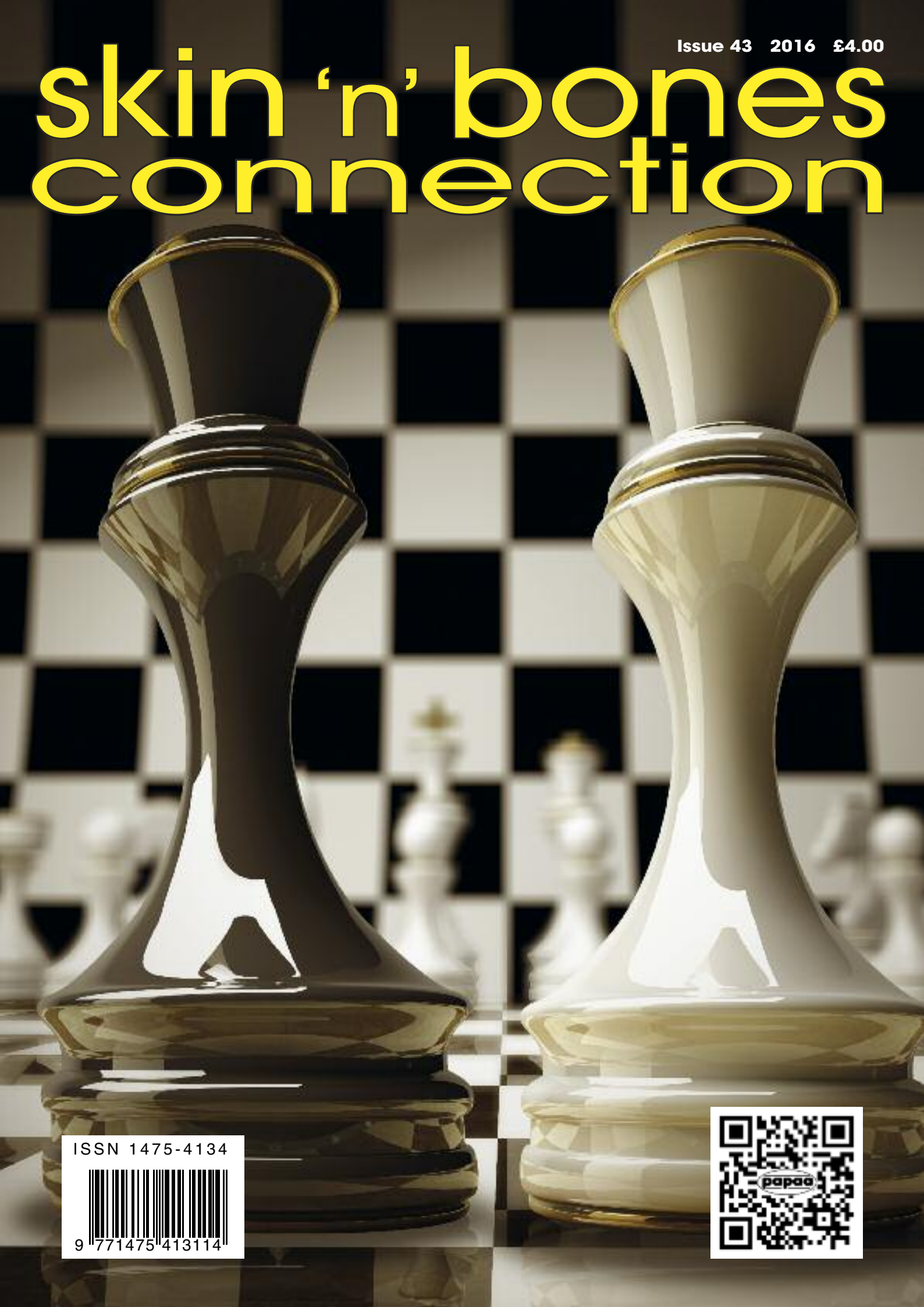
skin 'n' bones connection



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Dear Reader

It is widely recognised that there is not one route of care that suits all individual circumstances; on page 3 we report on a pilot study about the role community pharmacists can play in care and support, and whether they can provide people with educational and management support.

Sometimes care is not always as it should be and the system fails; on page 6 there is report on how people are not being prepared for the realities of having psoriatic arthritis and the impact it can have.

As with most things in life, the better we understand, the world we inhabit and the processes involved (in this case the UK healthcare system), the more confident we are in getting the most out of it. In a series of articles (pages 4-5 and 8-11), PAPAA's medical advisor, Dr David Ashton, aims to provide answers and explanations of how to understand and interpret technical terms and what the data in reports and research trials mean.

Finally, supporting people affected by psoriasis and psoriatic arthritis, is the main focus of what we are trying to do, and your involvement is vital. On pages 12 and 13, we report on some recent brilliant efforts from individuals who have raised money for PAPAA. That is not the only way people can get involved, on page 15, are examples of other ways you can get involved and turn your experiences into useful support and feedback.

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The Psoriasis and Psoriatic Arthritis Alliance (PAPAA) is the new single identity of the Psoriatic Arthropathy Alliance and Psoriasis Support Trust. The organisation is independently funded and aims to be a definitive source of information and educational material for people with psoriasis and psoriatic arthritis in the UK. To be a support to both patients and professionals by providing material that can be trusted (evidence based), which has been approved and contains no bias or agendas. We will be looking to provide positive advice that enables people to be involved as they move through their healthcare journey in an informed way, which is appropriate for their needs and any changing circumstances.

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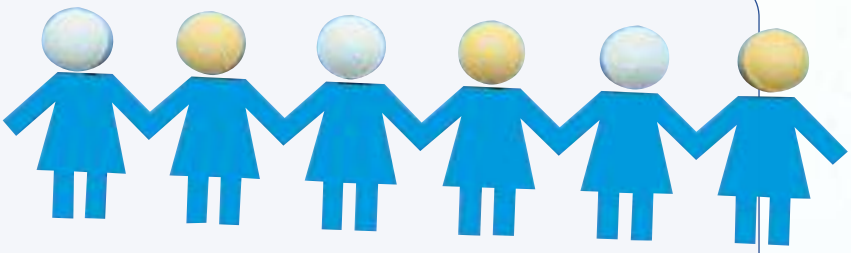
COVER PHOTO:

Healthcare can sometimes feel like a strategic game of chess, where we all have a view about which piece is the most important.

Chess Queen pieces image from Shutterstock © Aroslav Neliubov



A recent study carried out by community pharmacist Dr Rod Tucker and colleagues examined the role of the community pharmacist in the management of patients with psoriasis. The specific question addressed was: *Is it feasible for community pharmacists to deliver an educational programme designed to help people with psoriasis self-manage as effectively as possible?*

A total of 47 patients with psoriasis were recruited through seven pharmacies. Pharmacists undertook a two-consultation intervention (two separate appointments), with patients prescribed topical treatments for psoriasis. At the initial face-to-face consultations, the pharmacist assessed patients' knowledge about psoriasis and its management and provided educational support to help facilitate a greater understanding of their condition. This assessment was made using a standard questionnaire called the Person-Centred Dermatology Self-Care Index (PEDESI) tool. Both disease severity and the impact on quality of life were also captured during this consultation, using the Self-Assessed Psoriasis Area and Severity Index (SAPASI) and the Dermatology Quality of Life Index (DLQI) questionnaires. A second consultation took place, approximately six weeks later, at which pharmacists re-assessed each patient's understanding and repeated the disease severity and quality of life measures.

At follow-up, the researchers found a significant increase in average PEDESI scores, suggesting a much better level of knowledge regarding psoriasis and its management. Similarly, average SAPASI scores were lower, suggesting that disease severity was significantly improved over the period. Finally, the average DLQI scores were significantly lower at follow-up compared with baseline, suggesting that in terms of quality of life, the disease burden for the patients had reduced. In particular, the proportion of patients for which psoriasis no longer had a negative impact on quality of life increased.

Overall, therefore, these results suggest that pharmacist-assisted support for patients with psoriasis improved patient knowledge regarding the proper use of treatments, which translated into significant reductions in disease severity and improved quality of life. This is very encouraging and suggests that pharmacists should play a much more proactive role in the management of patients with psoriasis.

There are two main problems with the design of the study, which the authors acknowledge. Firstly, the number of patients recruited is very small and this obviously makes it more difficult to be confident about the conclusions. One must acknowledge, however, that recruitment for this type of investigation is extremely difficult and the author actually did well to finally recruit the 47 participants.

But the main problem is the lack of a control group by way of comparison. Ideally patients would have been recruited into the study and then allocated (randomised) into either the pharmacist-led intervention group, or the usual treatment group. The results observed could then be compared and the conclusions drawn would be much more robust.

Despite its obvious limitations, this pilot study is very important and points towards the need for a much larger, randomised trial.

The study was funded by PAPAA, via a small grant scheme. PAPAA supports well-run medical research in the following ways:

- supporting research by providing research grants
- promoting research programmes
- publicising results of research
- helping to recruit into research.

PAPAA is open to applications for funds via grant-giving process. For more information go to www.papaa.org/ research
PAPAA meets the criteria for NIHR Partner Organisation status for its Research Grants funding stream.
Therefore, PAPAA is an NIHR Partner Organisation in respect of its Research Grants funding stream.

Studies funded through this funding stream are eligible for inclusion in the NIHR Clinical Research Network Portfolio and therefore able to access NHS support via the NIHR Clinical Research Network infrastructure.

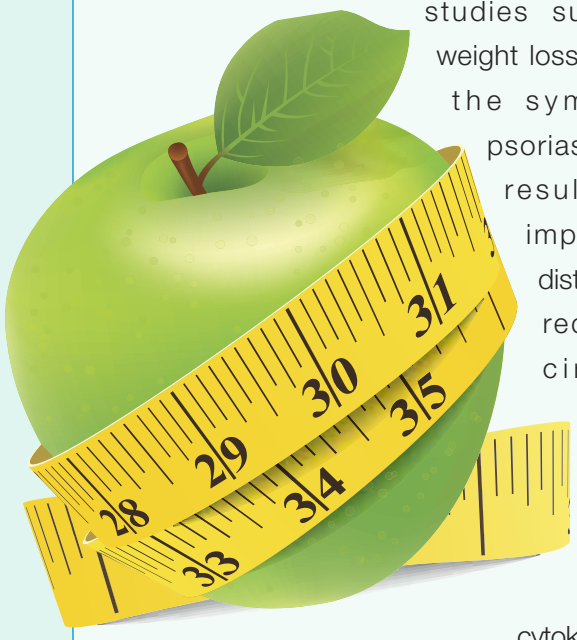
You can find further information about the NIHR Clinical Research Network Portfolio at:
www.crn.nihr.ac.uk

In the news

In a series of occasional articles, Dr David Ashton MD PhD, PAPAA's medical and scientific adviser, will look at stories which have appeared in the news or have been reported at meetings and explain the science behind them.

Weight-loss surgery and psoriasis

If you are predisposed to psoriasis (have or family history) it is well recognised that obesity is a risk factor for developing or worsening of psoriasis and psoriatic arthritis, and precedes the onset of these conditions in many cases. There is also evidence to show that being overweight reduces the therapeutic benefit of many of the medications used in psoriasis. In other words, if you are overweight you are more likely to get psoriasis and the medications used in treatment will be less effective. Exactly why there should be such a strong association between psoriasis and obesity is not entirely clear, but both can be regarded as fundamentally inflammatory conditions. Evidence shows that fat cells produce molecules called adipokines and cytokines, which drive the underlying inflammatory response and thus make psoriasis and arthritis worse. It follows that the impact of weight loss on psoriasis is of great interest to both doctors and patients alike. Several studies suggest that weight loss can improve the symptoms of psoriasis, probably resulting from improved drug distribution and a reduction in circulating levels of inflammatory molecules (adipokines and cytokines).



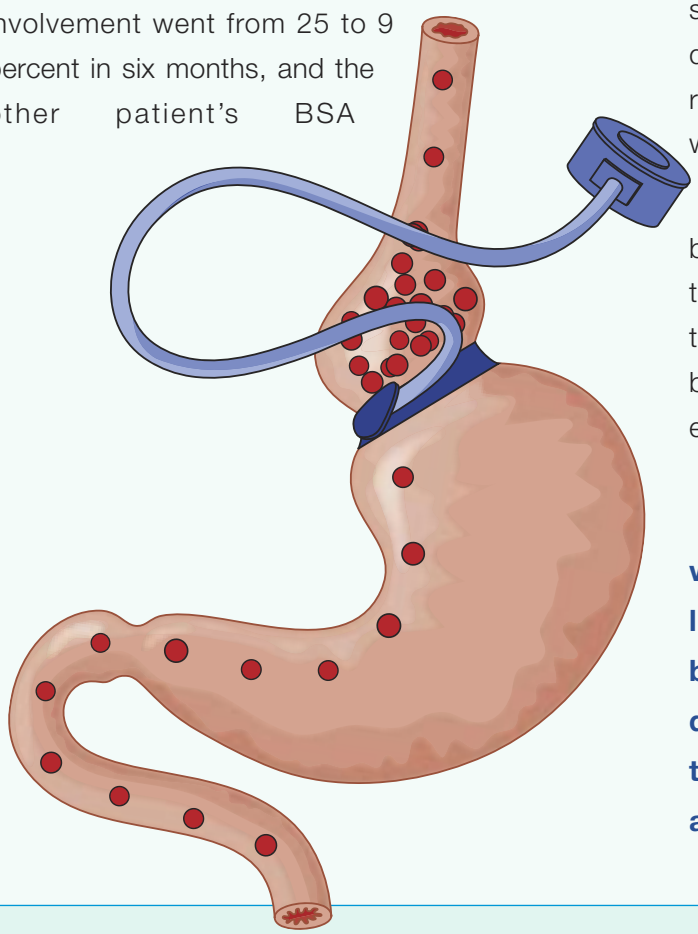
Over the past two decades, there has been a rapid increase in the numbers of obese patients undergoing a surgical weight-loss procedure (bariatric surgery). There is impressive scientific evidence to show that bariatric surgery delivers substantive, durable weight-loss with major improvements in associated diseases such as diabetes, hypertension and abnormal blood fats. In fact a surgical weight loss procedure has been shown to be the only really effective treatment for chronic obesity. Moreover, those undergoing a surgical weight-loss procedure have a substantially lower risk of premature death and disability when compared with their non-surgical, obese counterparts. **So an intriguing question is; what impact does bariatric surgery have on psoriasis?**

At the 2015 Annual Meeting of the American College of Rheumatology, researchers from New York University presented some interesting results of a group of 86 patients with psoriasis who were included in a larger group of more than 9,000 individuals undergoing weight-loss surgery. The patients with psoriasis were asked to rate on a scale of zero to 10 the degree of improvement they saw in their psoriasis (or psoriatic arthritis) following surgery.

More than half of patients with psoriasis and 62% of patients with psoriatic arthritis reported that their disease improved. Importantly, patients who had more severe psoriatic disease to begin with experienced more improvement, according to the data. The improvement in arthritic symptoms is almost certainly attributable to reduced weight placing much less stress on inflamed joints.

The problem with this study is that it was retrospective. Asking patients to try to remember what

their psoriasis was like before surgery is clearly unreliable because it introduces what is referred to as "recall bias". Researchers are now engaged in a prospective study in which patients with psoriasis are identified prior to surgery. This will allow a more reliable comparison to be made between pre- and post-operative symptoms. Nevertheless, other studies among obese psoriatic patients have shown that weight loss induced by bariatric surgery may decrease the severity of psoriasis, or eliminate it altogether, in anywhere between 40-60% of patients. In some individual cases, the improvements may be dramatic. For example, in two patients who underwent gastric bypass surgery, one patient's body surface area (BSA) involvement went from 25 to 9 percent in six months, and the other patient's BSA involvement went from 75 to <5 percent over the course of six years. These studies have led some to suggest that bariatric surgery – especially the gastric bypass – may be a viable treatment option for patients with severe psoriasis.



However, around one-third of psoriatic patients do not experience any skin or joint improvement after bariatric surgery and some (around 10-12%) may actually experience a worsening of their symptoms. Why should this be the case?

Scientists believe a possible explanation for surgical "non-responders" is to do with what is called the microbiome. This is the population of microbes living on and in us, especially in the gut. We each have around 10 trillion cells in our bodies, but we act as host to around 100 trillion bacteria. The gut alone, which includes our stomach and intestines, is home to about three pounds of bacteria. It is now recognised that these microbes play an important role in maintaining a healthy immune system and that an imbalance in gut bacteria could contribute to a "misfiring" of the system so that the body attacks its own tissues (autoimmune disease). This results in the typical inflammatory response of psoriasis. So what has this to do with weight-loss surgery?

It turns out that bariatric surgery (particularly gastric bypass) can alter the microbiome, but it may not be to the same degree in all patients. This variation could therefore explain why some patients undergoing bariatric surgery do not experience any benefit or may even experience a worsening of their psoriasis.

Put simply, the ultimate effect of a surgical weight-loss procedure on psoriasis may be largely determined by an individual's gut bacteria. This in turn raises fascinating questions about the microbiome and whether there are ways to harness it in the treatment and maybe even prevention of psoriasis.

System failure

Health system fails to prepare patients for reality of psoriatic arthritis.

- **Researchers interviewed 24 people with this type of arthritis.**
- **Participants sometimes thought of suicide or drank excessive amounts of alcohol as a result of their condition.**

In a new University of Manchester study, people with psoriatic arthritis have told researchers about the condition's deeply damaging mental effects and how healthcare services failed to prepare them for its reality.

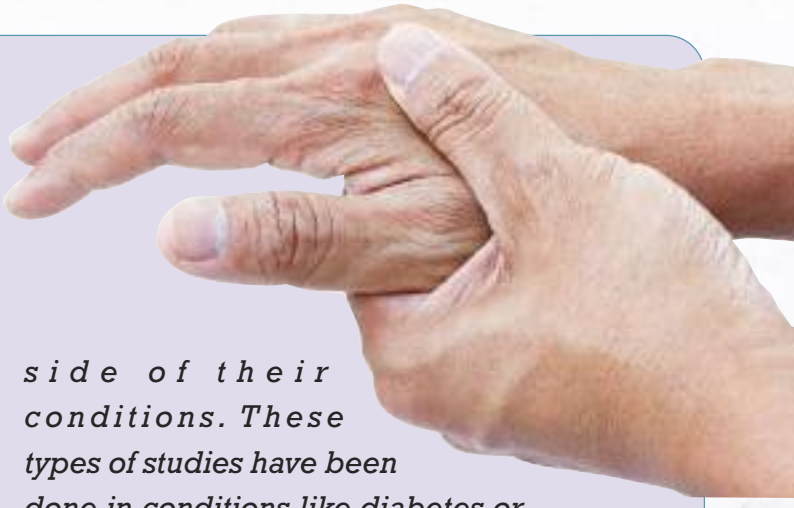
In the study, published in the journal ***Rheumatology,*** the researchers interviewed 24 people with this type of arthritis, which develops in 7-48 percent of people with the skin condition psoriasis. It causes painfully inflamed joints and, in some cases, associated mental health problems for those who develop it.

The study found that the participants sometimes thought of suicide or drank excessive amounts of alcohol as a result of their condition. Many felt resentful of others and socially awkward - citing it as a reason for failed relationships and career prospects. Many felt that the prospect of these feelings was not communicated to them at the time of diagnosis.

Dr Christine Bundy from the university's Institute of Inflammation and Repair and Salford Royal NHS Foundation Trust led the study.

She said:

"People in our study were often diagnosed but then left with little or no support for the emotional side of their conditions. These types of studies have been done in conditions like diabetes or cancer, but not in psoriatic arthritis.



"There's an urgent need for this research though as some of the participants were under the incorrect impression that their arthritis would clear up eventually or were suffering from extremely negative feelings."

One of the recommendations of the study is that more account is taken of the emotional damage caused by the condition, by improving resources such as websites and leaflets. More psychologists, particularly those with a specialist interest in rheumatism, should also be involved during the course of treatment.

Bundy added, *"The problems that came to light in this study are all treatable. With the right help and information, people can gain more confidence and recover quality of life. The prevalence of suicidal thoughts among this group is not yet known, but where it exists, effective and timely help could make a difference."*

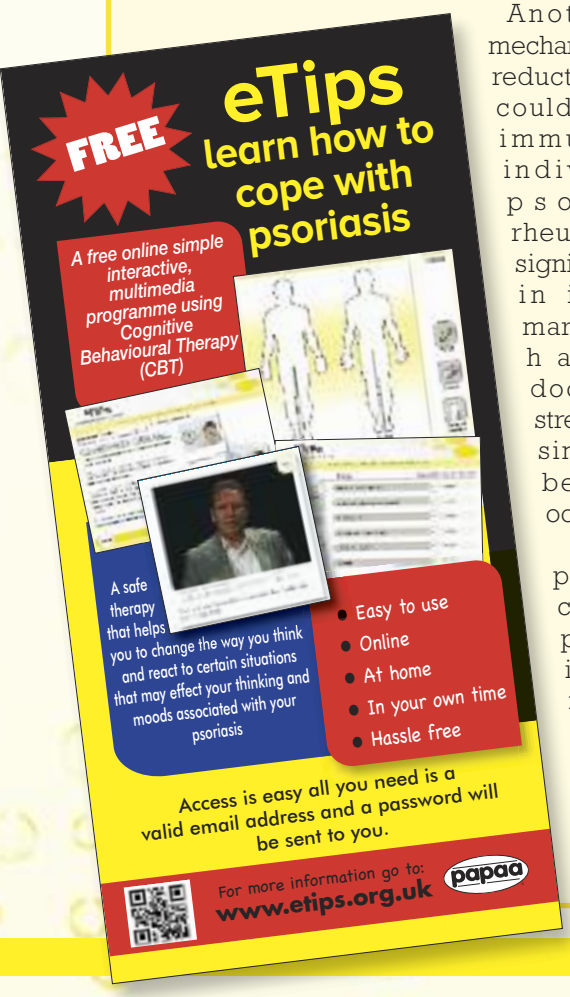
Paper, 'Distress, misperceptions, poor coping and suicidal ideation in psoriatic arthritis: a qualitative study', was published in *Rheumatology*'. doi:10.1093/ rheumatology/kew009

Source:
University of Manchester

An interesting report from the International Psoriasis Council (IPC) Workshop on the Role of Stress in Psoriasis was recently published in Frontiers in Psychology (2016). It confirms the important role of stress as an underlying factor in psoriasis and, importantly, the potential role of various stress management techniques as an aid to treatment[1].

The IPC is a not-for-profit charity organisation based in the USA and this workshop actually took place in Boston in November 2013, though the report has only just been published. The panel brought together dermatology and psychology experts from all over the world in order to review the current scientific evidence on the role of psychological factors (especially stress) in psoriasis. They were also asked to make recommendations regarding stress-management interventions in clinical practice.

Stress is a well-known exacerbating factor of psoriasis, which can make psoriasis worse and psoriasis can make you feel stressed. Exactly how and why this happens is not entirely clear, but there are some hints from recent research which may point the way. One possibility is that levels of stress hormones, such as cortisol, may be influenced by stress and that this may make the problem worse. However, new research suggests that stress relief interventions can lead to changes in the cortisol response of stressed individuals and an improvement in psoriasis symptoms and quality of life. It can also lead to a reduction in treatment duration when used in conjunction with certain standard treatments for psoriasis, such as phototherapy.



Another possible mechanism is that stress-reduction programmes could improve the immune status of individuals with psoriasis. In rheumatoid arthritis, significant reductions in inflammatory markers (cytokines) have been documented after stress reduction and similar immune benefits may also occur in psoriasis.

Two recently published reports confirm that psychological interventions can make a significant difference to psoriatic symptoms. The first of these studies used a simple technique called mindfulness, which is actually just a form of meditation. Twenty-nine people with psoriasis were randomised either to mindfulness treatment plus their usual psoriasis therapy, or to a control group which continued with usual psoriasis treatment alone. The subjects completed self-reported measurements of psoriasis severity, perceived stress, distress and quality of life (QoL), at baseline and again post-intervention. The mindfulness group reported statistically lower psoriasis severity and better quality of life scores than the control group[2]. Whilst this is a small study, it does suggest that mindfulness could be an effective adjunctive treatment (given in addition) in patients with psoriasis.

Another interesting study, supported by PAPAA, used a novel web-based approach to deliver a simple cognitive behavioural treatment (CBT) programme to patients with psoriasis. The full title was "The electronic Targeted Intervention for Psoriasis Study" or (eTIPS)[3]. This was the first online CBT intervention for people with skin disease and showed improvements in anxiety and quality of life, though not in psoriasis severity. Unfortunately the results were limited by a large drop-out rate and missing data, but this study nevertheless points the way to providing more easily available access to online psychological treatments for patients with psoriasis.

In conclusion, the IPC report confirms that increasing levels of stress in patients with psoriasis can result in a significant worsening of symptoms. Recent evidence suggests that this negative clinical response may be related to abnormal levels of cortisol or changes in the immune status of susceptible individuals. However, there is increasing evidence to suggest that this stress response may be improved with stress-management interventions. The development of web-enabled (e-health) approaches offers a flexible, inexpensive and patient-tailored approach to stress reduction in this population.

References

1. Schwartz J, Evers A, Bundy C and Kimball AB. Getting under the Skin: Report from the International Psoriasis Council Workshop on the Role of Stress in Psoriasis. Frontiers in Psychology; February 2016; Vol 7; Article 872
2. Bundy C, Pinder B, Bucci S, et al. A novel, web-based, psychological intervention for people with psoriasis: the electronic Targeted Intervention for Psoriasis (eTIPs) study. Br J Dermatol. 2013; 169(2):329-36.
3. Fordam B, Griffiths CE, Bundy C. A pilot study examining mindfulness-based cognitive therapy in psoriasis. Psychol Health Med. 2015: 20: 121-7.

Author:
Dr David Ashton MD PhD, PAPAA's medical and scientific adviser

Many of our readers and visitors to our website are very interested in the latest research on psoriasis, psoriatic arthritis and innovative treatments. Sometimes it can be difficult for non-scientists to make sense of the significance of a set of results, simply because they are not familiar with the technical terms used. The other problem is that the media quite often get things wrong and have a tendency to overstate the importance of a particular study, just because it grabs the headlines. This is why almost every week you can read about a medical "breakthrough" which almost never turns about to be anything of the sort.

The following will provide a straightforward guide to help you make your own assessment of a piece of research, rather than relying on the opinions of health journalists with their own agenda.

Study design

One of the most important aspects of assessing the quality of a particular study is to see how the researchers went about organising it. This is called study design or methodology. As we'll see, this has a major influence on the reliability of the results and the conclusions we are entitled to draw from them.

Experimental versus observational studies

There are basically just two kinds of clinical studies – those that involve doing something to patients (experimental) and those in which researchers simply observe patients without doing anything to them (observational).

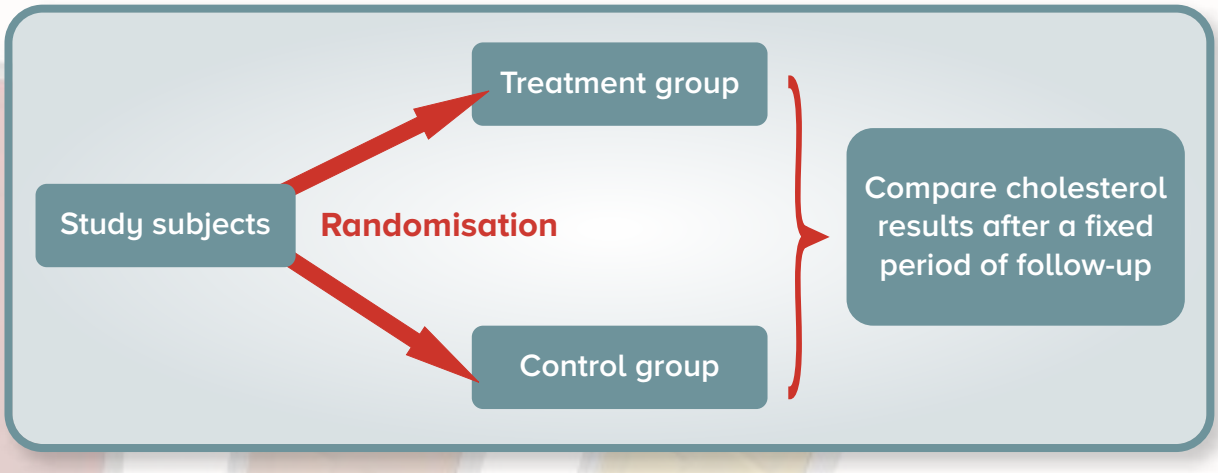
There are different study designs within each group and there is an overall hierarchy (ranking) separating the strongest from the weakest (see diagram below). In other words, the best evidence comes from randomised trials and the weakest from expert opinion.

So let's work our way down this hierarchy of evidence and make some brief observations as we go. First up, randomised controlled trials (RCTs).

Randomised controlled trial (RCT)

This is the "gold standard" in terms of evidence. The RCT is an experimental study in which a treatment is randomly allocated to one group, whilst the other acts as a control.

For example, suppose we want to study a cholesterol-lowering drug. We identify a group of patients with high cholesterol levels and we randomly allocate them into two arms of the study - those who will have the drug (treatment group) and those who will not (control group). The random allocation of individuals into these groups is important so as to avoid bias. It ensures that the characteristics of those in each treatment arm are broadly similar and so any differences in outcome are unlikely to be explained by baseline differences between the groups. Nowadays, study participants



are given a number and a computer randomly assigns an individual to one group or the other.

The subjects are then followed for a period of time – say six months – and the cholesterol levels of both groups are measured again. Any observed reduction in cholesterol levels in the treatment group is likely to be due to the medication rather than to chance or any other factors. At least that's what we hope!

It is precisely the presence of a control group that makes the RCT so powerful. If there was no control group and a reduction in cholesterol levels was found in those taking medication, it could be due to chance or some other factor (for example changes in diet) rather than the medication itself. Having a control group makes it reasonable to assume that any reduction in cholesterol levels observed in the treatment group is due to the medication alone.

So when you evaluate any study, ask yourself "was there a control group?". If not, the study is very much weaker, because without it one can never be sure whether the observed changes could have occurred by chance or due to other factors.

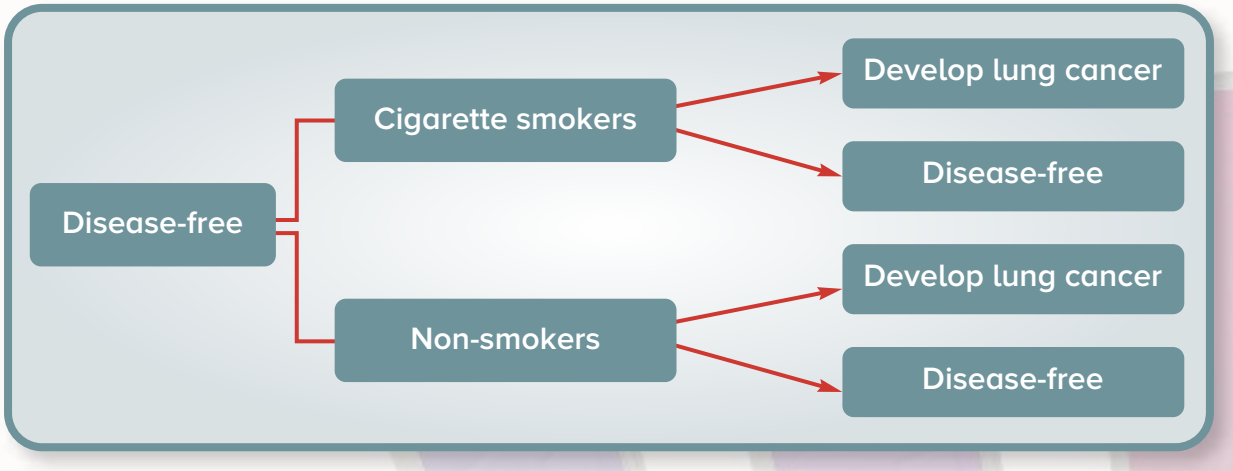
RCTs are often expensive and very complex to carry out, so they are less common than other study designs. They are almost always required for drug studies where the highest quality of scientific evidence is required by regulatory authorities before they are willing to grant a licence.

Cohort studies

These are studies in which a population of people (cohort) is followed over time to assess the incidence of disease. Researchers are often interested in whether the presence of certain possible risk factors actually increases the risk of a disease. These studies can be retrospective (historical) or prospective.

Suppose we want to establish whether cigarette smoking is a cause of lung cancer. A prospective cohort study as shown below could give us the answer. We identify two groups of patients, one cigarette smokers and the other non-smokers. We follow these patients over time and then compare the rates of lung cancer in the smokers compared with the non-smokers.

The famous Framingham heart study is an excellent example of a prospective cohort study. In the 1960s a large number of men and women were enrolled into the study (based in Framingham, USA) and their baseline characteristics, including cholesterol levels, blood pressure (BP), physical activity patterns, smoking habits, and body weight were measured and recorded. At the time of enrolment they were all free of disease and the researchers then followed the patients annually to see what happened to them. After decades of follow-up, researchers were able to confidently identify those factors which were the strongest predictors of heart disease – diabetes, BP, raised cholesterol and cigarette smoking.



Nowadays these are simply referred to as risk factors.

Case-control studies

These are retrospective studies in which patients with a disease (cases) are compared with patients who do not have the disease. Using the previous example of smoking and lung cancer, we collect the files for lung cancer patients and we look back at their history to see what proportion of these patients were smokers. At the same time, we collect files from a group of patients who do not have cancer and see how many of this group were smokers (controls).

We can then see what proportion of those with and without lung cancer were smokers. In the case of smoking and lung cancer, we would obviously expect to see a much higher proportion of lung cancer cases among the smokers.

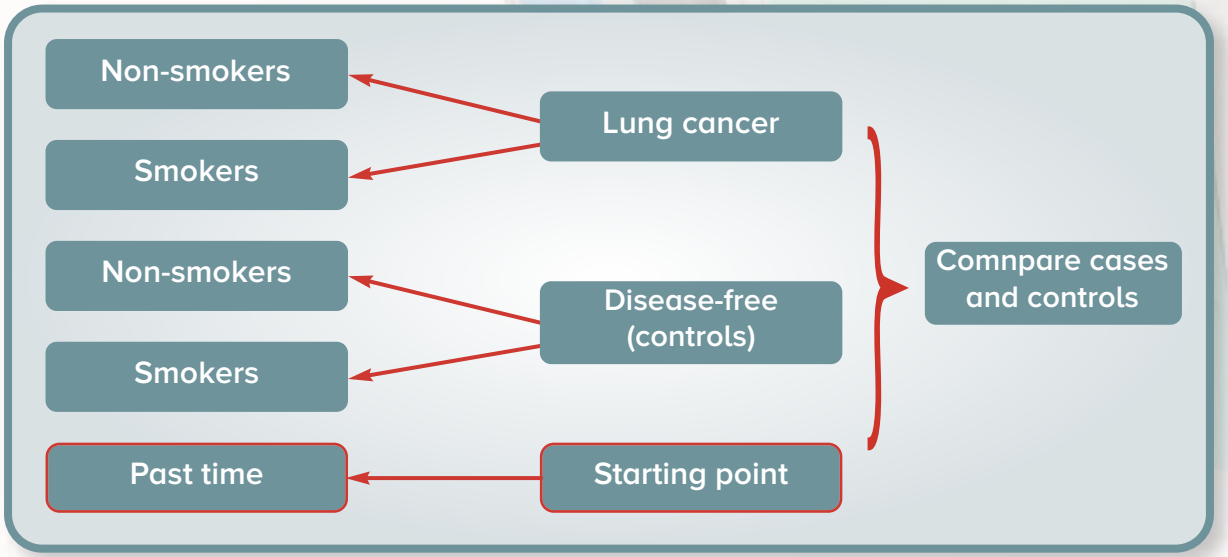
Case-control studies are relatively easy to do and inexpensive (though time-consuming). However they have lots of potential sources of error and bias which are not always easy to overcome.

Cross-sectional studies

In a cross-sectional study, data are collected on the whole study population at a single point in time, to assess the prevalence of a particular condition and its relationship to other factors. In other words, it provides a snapshot of the frequency of a disease in a population at a given time.

As an example, suppose you would like to know about the burden of childhood asthma in a population of 12-14-year-old schoolchildren in London. You would identify a number of schools and arrange to interview the children and establish how many were on medication for asthma. You might do this over a period of one month. So what this study will tell you is how common asthma is in this population of children at this point in time.

A cross-sectional study may also give some clues



about other factors of interest. For example, if you were to enrol a number of schools into the study, say three inner-city schools and three rural schools, it would be possible to explore the relationship between the frequency of asthma and levels of air pollution. Equally, if you know the parents' smoking habits, it would be possible to assess how this relates to the frequency of asthma in the children.

One of the difficulties with cross-sectional studies is identifying a suitably representative sample of subjects. However, because they do not require any follow-up, they have the advantage of being relatively simple to carry out.

A major limitation of cross-sectional studies is that they can tell you nothing about the causes of disease, because risk factors and diseases are present simultaneously. So you cannot be sure which came first – the high cholesterol or the heart attack. This is why the causes of disease need to be confirmed by more rigorous studies

Case series/case note review

These are written reports which are essentially descriptions or accounts of individual patients with particular conditions, or a series of such patients.

According to our research hierarchy, case series are at the bottom of the reliability scale, along with expert opinions. But, despite this lowly position, there are many instances where valuable knowledge has come from someone taking the trouble to write up cases that are rare or in some other way unusual. When such reports are published, they can often alert other doctors to the problem and may stimulate further investigation. Sharing information this way is extremely valuable and is potentially of great benefit to patients.

Expert opinion

It may seem odd that the opinion of experts is placed at the very bottom of the reliability scale for evidence, but there are compelling reasons for this.

Firstly, opinion is not evidence. It is very easy to make assertions about things, but more difficult to provide evidence to support it. As senator Patrick Moynihan rightly said, ***"Everyone is entitled to his own opinion, but not to his own facts".*** Even the

most learned and distinguished scholars and scientists can be wrong and history is full of examples of this.

Secondly, opinion is almost never objective. All of us – even scientists – have perspectives and views which are biased in one way or another. If I work for a drug company that pays my salary and we develop a new drug for psoriasis, the chances are that I am going to be somewhat biased in favour of it. This is just human nature and is precisely why we have randomised trials to remove this sort of bias.

So the lesson is that we should never be convinced by opinion alone. If the evidence conflicts with the opinion, then it's wrong. It doesn't matter whose opinion it is, or how important or famous they are, if the evidence does not support their claim, they are wrong. That's it!

Of course, none of this is to say that expert opinion is worthless. For example, the experience of a senior surgeon extends well beyond that of clinical trials and could never be captured by them. But the practice of surgery itself and the best approach to treating specific clinical conditions must always be evidence-based.

Author:
Dr David Ashton MD PhD, PAPAA's medical and scientific adviser

Martin and Paul's West Highland Way Adventure

This year, Martin Watson and Paul Sinclair are going to embark upon the West Highland Way; a fair trek from Milngavie to Fort William.

It is the hope that this endeavour will raise lots of money for PAPAA. Martin knows how crippling this condition can be, and suffers badly from it on his feet. Nevertheless, this is not going to stop him from walking the 95-mile route with one of his oldest friends by his side.

The adventure will see our 40-something-year-old hikers walk about 14 miles per day through rugged terrain and beautiful scenery, camping for the majority of their nights and tackling all that the Scottish Highlands have to throw at them.

The West Highland Way is not a walk in the park, and will be a challenge for these two men, who will have to overcome much to reach the end of their journey. Furthermore, Martin's late brother Phil will be in their thoughts during this venture, as he too suffered from psoriasis.

Thank you for your support.

Ben Smithson's London Marathon 24th April 2016

"I guess the first question I have to ask myself is why I wanted to embark on this crazy endurance race? The simple answer is that I wanted to prove to people that no matter how hard things get, when you put your mind to something it is achievable. I have suffered with psoriasis all my life and contracted psoriatic arthritis when I was 17. At times it has been extremely hard to deal with. Having to deal with the psoriasis is fine but it is more the fatigue and energy levels that you have to overcome and manage as best as possible.

Starting this challenge was a great commitment as running a marathon takes an awful lot of dedication and time, but it was something that I personally wanted to achieve to not let this disease get in the way of my life. I have been extremely fortunate that the medication I take has been extremely successful in reducing and eliminating the psoriasis and psoriatic arthritis.

Coming into the final training stages of the marathon you always ask yourself have you done enough and then the butterflies start to flutter and the nerves creep in! The day itself was a momentous occasion. I have never experienced an event like it; from the organisation to the support, the whole thing was a complete success. It truly was a magical day and I am so pleased that I took part in this race. I managed to raise around £4,000 for the charity and to give something back to all of those who have helped me through this is what it was all about. The support that I received from my family and friends was amazing and I could not have done this without them.

So my message is that no matter how hard it gets, just put your mind to it and you will get through; have the determination and the strength to succeed."

Well done and thanks Ben from everyone at PAPAA for your tremendous effort and support.

A grand day out

At the beginning of July, Yorkshire Dales Centre of The Caravan Club (www.ydcc.co.uk) held a rally in Ripon, with all the proceeds from the event in aid of PAPAA.

The chairman of YDCC, Howard Jennings said:

"...my daughter Suzie who is 33 years old was diagnosed with psoriatic arthritis early last year and because of this, I pledged to her that I would raise funds for PAPAA."

"...we had forty caravans attending. Throughout Saturday we had fun and games, live music, food, tombola, auction and a raffle to raise funds..."

Total raised for PAPAA was £1,435, which is the largest amount ever raised by a chairman in the forty year history of the centre.

PAPAA would like to thank Howard, his wife Margaret, their daughter Suzie and all the members of the club who attended the rally, for their generous support.

If you feel inspired to hold an event, or want to raise funds for PAPAA, more details of how to, below.

Howard Jennings getting a soaking in aid of psoriasis and psoriatic arthritis.

Katie's Peak District Triathlon at Chatsworth

Katie Shipley will be swimming 1000 meters in the river Derwent as part of a team triathlon in July 2016, but that is just the main event. For her training she will be spending a lot of time swimming at Dearnford Lake in Whitchurch, freezing her toes off! **Good luck Katie!**

You can support any of those raising funds by visiting our Just Giving page: www.justgiving.com/psoriasis/donate

If you feel inspired and want to get involved, then we are happy to support your efforts.

Not everyone can run a marathon, walk 100 miles, take on a major swim, cycle or abseil. The following are a few ideas of what you can do, including:

- **Grand prize draws/Raffles**
- **Garden fetes/Plant sales/Craft sales**
- **In memoriam/Donations**
- **Car boot sales**
- **Sales of T-shirts, pens, key rings etc**
- **Quiz nights**
- **Coffee mornings/Cake sales**
- **Distribution of information**
- **Awareness activities**
- **Poster/leaflet distribution**

If you would like to take part in or hold an event on our behalf or you have any ideas or need support, advice or promotional items, please contact us:

If you have any ideas or want to raise funds for PAPAA we are always open to suggestions.

Visit www.psoriasis-shop.org and click the promotional products page.

Suggestions for new products to add to our range welcomed.

Roadmap launched

The British Society for Rheumatology (BSR) recently launched a report setting out a programme of work to enhance care for people with rare rheumatic and musculoskeletal conditions.

A collaborative approach to improving outcomes in rare rheumatic and musculoskeletal diseases builds on a national workshop hosted by the BSR in November 2015, which brought together a range of interested individuals (stakeholders) to help raise the priority of rare rheumatic and musculoskeletal conditions and improve patient care.

A key theme to emerge from the workshop was the need for greater cross-sector collaboration and this report sets out a number of recommendations, including the need to:

- work to improve condition knowledge across all health professionals
- create a rare rheumatic and musculoskeletal partnership, building on commonalities across these conditions to foster closer collaboration and knowledge sharing
- develop national audits for rare conditions to help measure and drive improvement in standards of care
- improve the data available to the NHS about these conditions through disease registries and adoption of specific rare disease coding
- promote the development of regional coordinated networks of care for rare diseases.

The report comes at an important time for rare diseases. Two years on from the launch of the UK Rare Disease Strategy, much of the focus has been on genomics and the 80% of all rare diseases that have a genetic origin. However, the BSR believes that greater priority should be given to the non-hereditary rare conditions, of which the rare inflammatory and autoimmune diseases are a very important component. These related conditions include ANCA associated vasculitis (AAV), lupus and scleroderma. People living with these conditions report delays in diagnosing and treating their condition of up to seven years. During this time their health may deteriorate with risk of permanent disability, organ failure, or even death. For example, 1 in 6 people diagnosed with AAV are likely to die within a year of diagnosis and life expectancy for people with lupus is 20 years shorter than the UK average.

A collaborative approach to improving outcomes in rare rheumatic and musculoskeletal diseases offers a first step in delivering a co-ordinated response to the needs of people living with these conditions. This view is underlined by Dr Peter Lanyon, BSR president and chair of the NHS England Clinical Reference Group for Specialised Rheumatology, who commented:

"This report sets out a vision of how the stakeholders within our community can work together to improve the lives of people with rare rheumatic and musculoskeletal disorders. These have largely gone under the radar of policymakers and those who commission and deliver health services. We hope to redress that through the collaborative approach outlined in this report, to ultimately help deliver better care and outcomes."

This sentiment was also echoed by Jane Dunnage, former chair of Lupus UK, who said, "People with rare rheumatic and musculoskeletal conditions, such as lupus, will be heartened by this report. It helps shine a light on this overlooked group of diseases which have such a significant impact on people's lives. We urge our partner organisations to support us in raising their profile and driving improvements to services for people with these conditions."

The report is available to download now at http://www.rheumatology.org.uk/includes/documents/cm_docs/2016/b/bsr_rare_conditions_report.pdf

About the British Society for Rheumatology:

The British Society for Rheumatology (BSR) works to promote excellence in the care of people with rheumatic and musculoskeletal disorders and to support those delivering it. Involving patients and carers at every step, BSR aims to ensure that physicians and clinicians are equipped to provide high-quality care. www.rheumatology.org.uk

Source:
BSR media release

Volunteer your time to help us

As a patient-centred charity, PAPAA is committed to patient and public involvement (PPI) and consults with people affected by both conditions. As part of that process, PAPAA has developed a psoriasis lay user group, which along with its medical advisory panel helps to provide positive solutions to manage psoriasis and psoriatic arthritis.

Role of the group

The group consists of representative volunteers who have the condition or who are directly affected by the condition; this may include partners, parents and children.

The role of the group is to provide PAPAA with front-line views of what is appropriate and relevant to patients, by identifying gaps and helping us to plug them. In most cases this will be to review output from the charity in the form of information, educational and awareness material, which is available freely to those who are most in need.

From time to time, the reviewers may be invited to contribute to wider consultations, surveys or to attend meetings (optional), which need input from people affected by the conditions.

PAPAA aims to be inclusive and wants to empower people to take an active part in the way that their disease is managed and treated within the four UK healthcare systems.

Involvement is not aimed at being too demanding and members are under no obligation to do anything with which they feel uncomfortable. Any contribution, however small, will be valued.

General comments and feedback

PAPAA also wishes to get feedback from non-group members who want to provide views and ideas. You can do this by adding comments on a page within our site or by sending them directly to us via the methods indicated on the contact us page.

PAPAA wants to hear from you and so do other people with these conditions. You can also provide comments via Facebook or Twitter

PAPAA Patient and Public Involvement Panel

If you would like to get involved in any of our psoriasis and psoriatic arthritis patient and public involvement activities, some internet routes of contacting us are below. More traditional methods are on page 2.

Internet contact

- www.papaa.org/contact-us
- PAPAA on Facebook https://www.facebook.com/papaa.org
- PAPAA on Twitter https://twitter.com/PsoriasisInfo
- Instagram https://www.instagram.com/the_papaa_eye/
- Pinterest https://uk.pinterest.com/psoriasisuk/

Share your story

On the PAPAA website there are a number of personal stories, submitted via our 'share your story' page. The following story was submitted and received many responses, when shared on social media.

"There are a number of things, which I often want to explain to people, but don't...

1. **I know I don't 'look sick' and I'm glad of that but sometimes it would be easier if I did. I might have made it to work (or wherever) today but it wasn't easy. People who know me and remark on my strength are a blessing.**
2. **Sometimes I will turn down your invitations and it's not because I can't come, it's much more complex than that. Sometimes the way I feel about myself is greatly affected by my psoriasis and psoriatic arthritis. My energy can also be in short supply, sometimes it needs reserving for the basics of life rather than going out.**
3. **Changing my diet won't 'cure' my conditions and the alterations that are known to control symptoms I have done for some time. I know you mean well but … neither will yoga.**
4. **I'm not too young to have arthritis… I wish I was, but unfortunately psoriatic arthritis is not linked to ageing and the disease sometimes kicks my butt.**
5. **Yes, I am quite warm wearing long sleeves but I prefer to cover my skin as I find it embarrassing and uncomfortable when people stare. Telling me I should ignore them doesn't personally help me.**
6. **Just because I'm driving or you saw me at the supermarket doesn't mean I'm ok. I'm quite a determined person and I work through the pain in order to keep some aspects of normality.**

I am 35 years old, was diagnosed with psoriasis at 22 and with psoriatic arthritis at 26. I'm currently awaiting UVB treatment again for my skin to give me some respite and to be reviewed by a rheumatologist for advice and treatment.

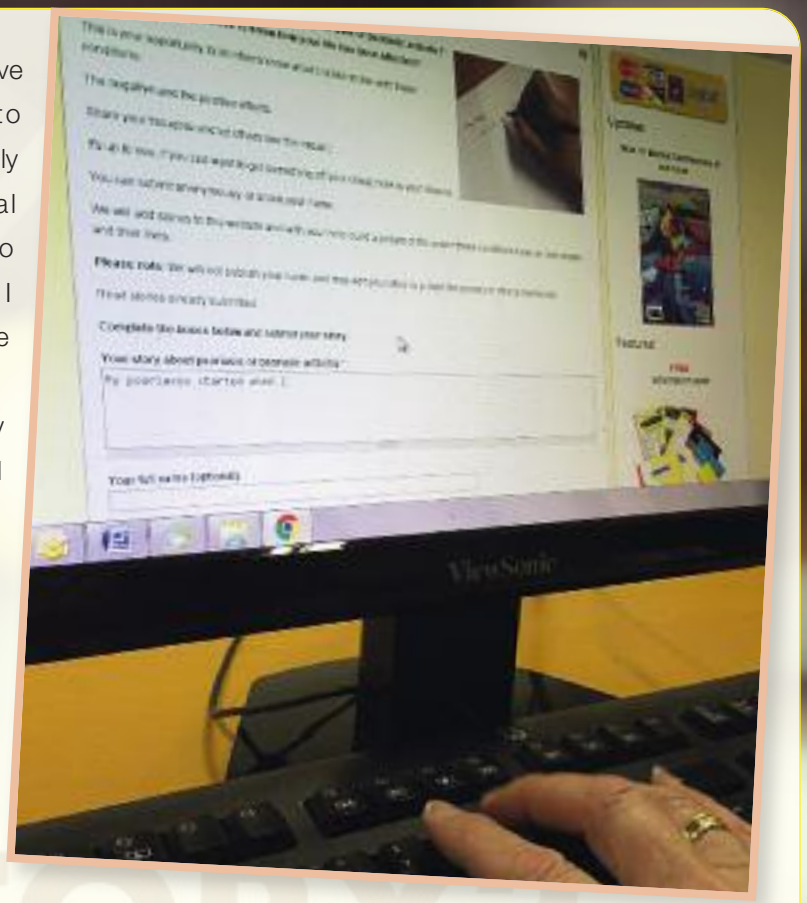
I have always taken myself to be one of those people that just 'gets on' with life; yes, I have my troubles with health but it has never really stopped me… or so I thought. In recent months both my psoriasis and psoriatic arthritis have flared up and most recently it has prevented me from working for the first time since diagnosis. It has been necessary to slow down and, inevitably, this has given me time to reflect on life and the reality of how I am impacted by both conditions.

Psoriasis, I have discovered, impacts my daily life in ways that those without it may never understand. I subconsciously plan everything out in my head and my brain is always ticking over.

Psoriasis affects the smallest parts of everyday life ... how I choose to wear my hair due to scalp psoriasis, the clothing choices I make to ensure the majority of it is hidden, the social activities I feel able to take part in, my confidence, my mood...the list could go on forever. I often get comments about my psoriasis not being 'bad' but people probably don't realise the efforts I go to in order to, in some way, hide it from the world.

Psoriatic arthritis, in my experience, is much more than just some aches and pains in my body. For me this condition leads to severe fatigue, stiff and sore mornings and disturbed sleep, to name but a few difficulties. Most

recently I have begun to notice not only the physical toll but also the mental. I can be quite emotional about my skin and joints at the moment. This is new for me. This is difficult.



Due to psoriatic arthritis flare-up in my hands and numerous other joints I am not able to go to my work at the moment. I have realised during these past few weeks that I might be somewhat of a workaholic. I am not good at taking time out or relaxing and I am finding myself overwhelmingly bored. Then there are the fights that I have with myself in my mind; due to the nature of my condition I have good and bad days. When I have a good day I feel guilty that I am not at work and think I should head back… then tomorrow comes. Bad day.

All of the above being said, I do firmly believe that life is still good and there are many positives to be found in every day. It is good to have time to reflect and be real and whilst psoriasis and psoriatic arthritis do affect my life they won't defeat me! *Shared by YS.*

A selection of the responses to this story via social media

"Hi, just sending my thoughts; this could have been written by me!

I had psoriasis as a child and it was around just over 10 years ago when my joints started. At the age of 40 I was diagnosed with PsA. I'm fortunate (I think!) that I have amazing medical teams/consultants who keep me upright. I do a full-time job in 4 days together with a bundle of meds including methotrexate, sulfazaline and humira. Yes totally. I don't look ill (yes, overweight, for a variety of reasons!), I love myself but by god there are some days that are incredibly difficult, some evenings extremely difficult to tolerate! Take care everyone, just do the best you can, enjoy when you can and only have people in your lives that love you for who you are!" *From SW*

"This resonates so much with me. I kept nodding 'yes' that's just like me! I was diagnosed with PsA at 19, 30 years ago, and am currently off work. I love my job and desperately want to be back but, having just started new medication that has severe side effects, I know I need to patient - with it and myself. I am lucky that family and friends understand the impact this has on my life but also that I refuse to let it define me. However, it is harder when meeting new people - sometimes I just wish I had a card that I could give them that sums it up without the emotional strain of having to explain." *From HS*

Share your story

"This sounds like me as well. I am now 56 years old and was diagnosed in the early '90s have tried every single drug going including chemo and all the different biological drugs. The latest one is not working so I am now sitting here with nothing but painkillers that really are not touching it. I am just about at my wits' end and fed up being a guinea pig for new drugs that are really for psoriasis and not for PsA. I don't know what to do any more." *From GS*

"I'm 66 and just diagnosed 3 months ago withPsA. It was triggered by a bout of West Nile virus. I have dactylitis in fingers and toes, the pain is for real. I can not put shoes on or walk barefoot, feels like the bone on my forefoot is on the ground! I tried methotrexate to no avail. See Rhuemy tomorrow to see what useless thing he will now suggest." *From SO*

"I've just had to give up my job as a rheumatology specialist nurse due to my psoriatic arthritis and a brain condition I have. I've battled through it all for the past few years but find I have hit a brick wall. Thanks for sharing this story." *From ET*

"I was diagnosed with psoriasis at 8 and psoriatic arthritis at 28 (32 now). Unfortunately by the time I was diagnosed with PsA the disease had severely progressed and I had bone damage. It has been very tough to explain to friends and family. Not everyone understands when you don't look sick. Thank you for sharing your story. It's good to know we aren't alone." *From SW*

"Completely understand how you feel. I am fortunate to have a relatively minor occurrence of psoriasis which is very much manageable. However a recent diagnosis of PsA has left me gutted. I'm exhausted, emotional and bloody sore." *From GW*

"Absolutely took the words right out of my mouth. I'm actually breathless at the moment. So articulate and honest in a way that only a sufferer could convey." *From JL*

"I don't have either condition but my other half does.

I've just been reading some of your stories to him. It is really frustrating that people assume he can't be that bad as he 'looks fine' and gets on with stuff. Just a question; does anyone suffer from a 'spaced out' feeling? We don't really understand why it happens and whether it's related to psoriatic arthritis or not. When it's really bad he struggles to concentrate or even put a sentence together." *From SH*

"Thanks for this. Very poignant for me today." *DP*

"I have quite recently been diagnosed with PsA after having psoriasis for years. I wake up feeling tired but wanting to take on the world, but by the time I have washed and dressed, I have to change my mind. People look at me and think I'm lazy, not drained from fighting the pain on a daily basis.

"It gets me down now and again but I keep saying to myself at least I'm alive. One Life - Live It." *From TA*

"I just wanted to say thank you for all the lovely comments in response to my story. I hadn't realised it had been shared on here as well as the web page and therefore just caught up with all the comments now. It is always encouraging to know that other people have similar and shared experiences. Thanks again." *From YS*

If you would like to share your story, you can at www.papaa.org/share-your-story or, if you prefer, send it to us via email to info@papaa.org or by post to:
PAPAA
3 Horseshoe Business Park, Lye Lane, Bricket Wood, St Albans. AL2 3TA.

Dear PAPAA

I wanted to pass on my thanks as I've found your website a great resource while I've been struggling with a recent bout of guttate psoriasis with severe tendonitis/enthesitis following strep throat.

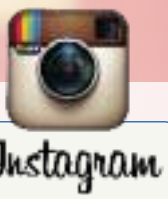
In particular your article 'Why do I feel so tired?' was tremendously reassuring at a time when my GP and dermatologist were strongly insisting that my symptoms were due to mental illness or an unrelated physical illness rather than psoriasis.

The line 'Some people who develop this symptom think there must be something psychologically wrong with them or that they are going mad' really helped me to continue pushing until I eventually received appropriate diagnosis and treatment (who knew you could pass the PEST* assessment and still have PsA?).

Thank you for the work you do.

V M

*PEST (Psoriasis Epidemiology Screening Tool) is a validated screening tool for psoriatic arthritis (PsA) and it is recommended that patients with psoriasis who do not have a diagnosis of PsA complete an annual PEST questionnaire (NICE psoriasis guidelines 2012). A score of 3 or more indicates referral to rheumatology should be considered.



Do you have a computer or smartphone? Do you want to share your experiences?

Visit the PAPAA Facebook page and read what other people are talking about. You can access the PAPAA page by clicking the link from our website home page.

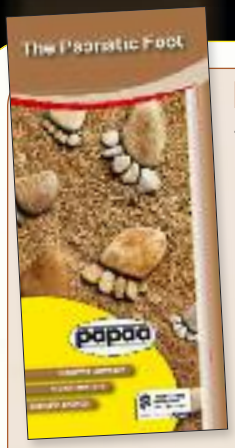
To-date, people have, been discussing tiredness, diet and disability claims, amongst other topics.

We post interesting news items and links to fuller articles on our website: www.facebook.com/papaa.org

We also have a Twitter page linked to our Facebook page so if you prefer the micro-blogging site you can follow us by clicking the link, which is also located on our home page: www.twitter.com/PsoriasisInfo

Follow us on Facebook

Marketplace



New leaflet: The Psoriatic Foot

The foot is a very important part of the human anatomy and is very sensitive to change. It has the role of carrying the weight of the body and acting as a sensor when walking or standing; any change or interruption of those functions can have a profound effect.

Psoriasis and psoriatic arthritis can affect a foot or both feet, causing significant problems to those with the conditions. In response to requests about the problems people face with their feet when they have psoriasis and or psoriatic arthritis, we have produced a new leaflet called ***The Psoriatic Foot***.

Reviewed by patients and leading experts it aims at helping people understand what happens to the feet when affected by psoriasis and psoriatic arthritis. Providing information on what can happen, diagnosis, treatments, where and when to seek advice. Also sections on other common conditions that can affect the skin and joints of the foot.

The Psoriatic Foot is available free to anyone and can be ordered in bulk by healthcare professionals for distribution via their clinics. The information has been produced under the Information Standard scheme, which requires the material to be accurate, impartial, balanced, evidence-based, accessible and well written.

During the review process, the following comments were received about the leaflet: ***"Having never been given any information regarding foot involvement of this condition, I was delighted to read the comprehensive detail for your leaflet on the same; it threw some light on what has and is happening with my own feet, so thank you."***

"A very informative leaflet, I have learnt a lot from reading it"

To get a FREE copy visit the PAPAA shop (www.psoriasis-shop.org). Alternatively you can download it as a PDF or plain text document. If you would like a hard copy, please contact us. See page 2.

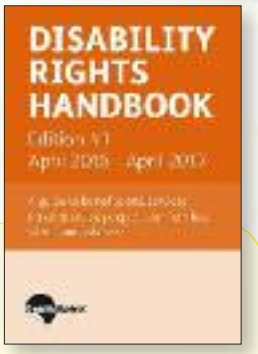
Visit the PAPAA shop

www.psoriasis-shop.org

- Order free information
- Join and pay for your subscription
- Renew your subscription
- Make a donation
- Purchase from a selection of books
- Training programmes.

PAPAA's position on pharmaceutical funding

PAPAA does not receive funds (either directly or in kind) from the pharmaceutical industry or commercial sector. All activities are funded via donations, subscriptions, charitable grants, legacies or other income generation. We believe that this allows us to act in an open, non-biased way and free from any perceived influence or agendas that may arise. We do not link our activities to commercial marketing or public relations campaigns and will only link our name or logo to an activity if we believe it is beneficial to our constituent group.



Disability Rights Handbook

- **Want to know what benefits you can claim?**
- **On benefits but not getting what you think you should be?**
- **Need to know how the recent legislative changes will affect your care package?**
- **Advice on benefits or independent living?**

The best guide there is to both disability benefits and independent living. Clearly written, in-depth information on the entire benefits and independent living system. Has the answers you need to claim what you're entitled to.

What's new this year?

Extended and updated to reflect cuts affecting benefits, including Universal Credit, Housing Benefit and Tax Credits, this year's Handbook, covering the continuing reform of social care, the new state pension introduced in April 2016 and the differences in laws covering Scotland and Northern Ireland.

Disability Rights Handbook Edition 41 - 2016-17 Price: £18.00 (concessionary price available if you are in receipt of benefits – limited to two copies per customer). £33.50 full price. **For full details visit: www.disabilityrightsuk.org**