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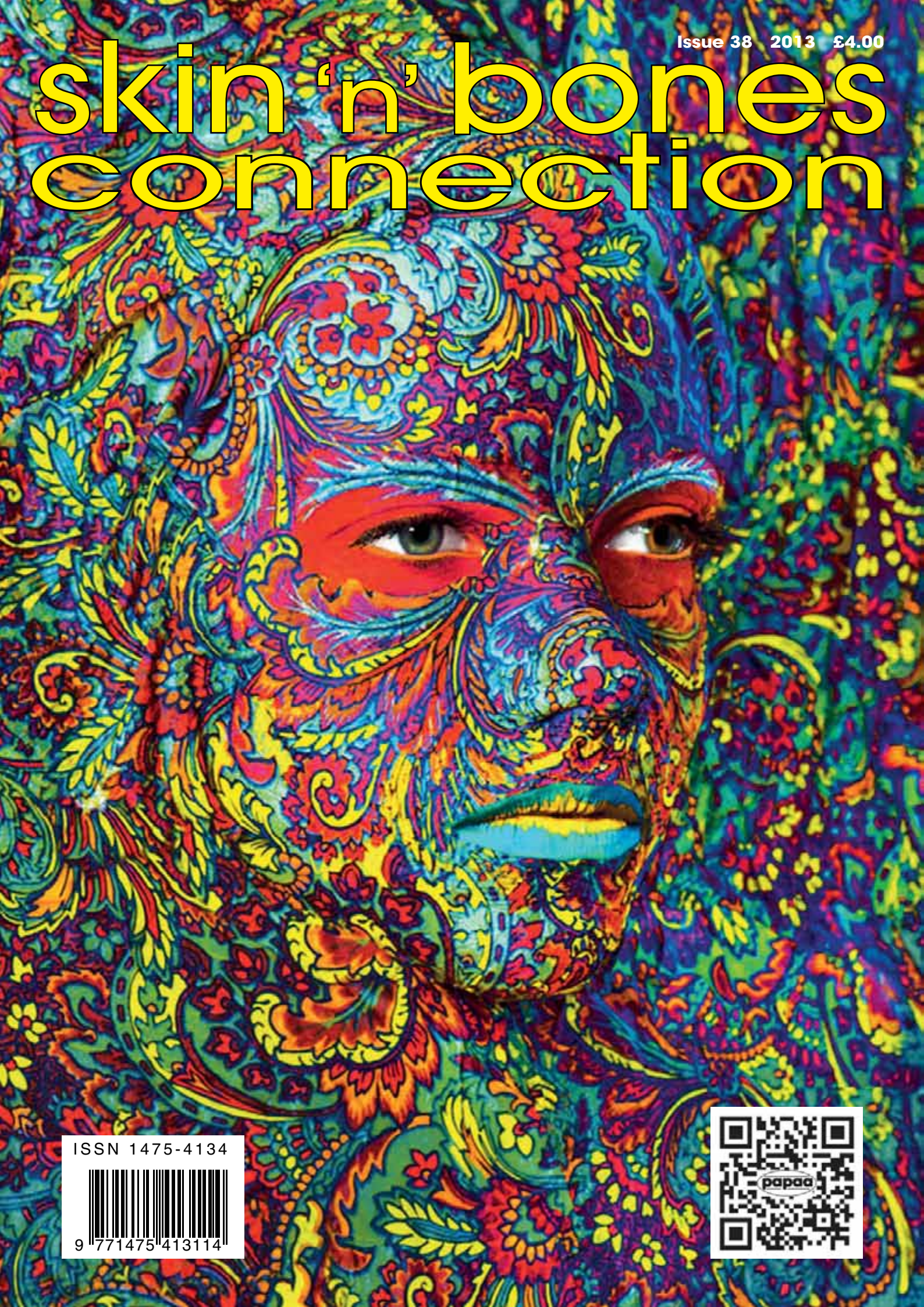

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Dear Reader

Psoriasis and psoriatic arthritis continue to be linked to other diseases, with increased risks of developing those comorbidities given a number to multiply the risk by. These are often expressed in terms such as 'double the risk' compared to that of someone without either condition.

When assessing such statements in the media it is always worth looking at the detail and whether they are qualified by severity of disease or other risk factors that might influence the risk, such as smoking, weight and alcohol consumption (pages 4 and 5).

It is also worth considering the perspective of the reporting, and the significance of the risk if it is reported against the general population. For example a risk of one in a million people might be considered low risk, therefore when it is said that the risk is doubled, that will be two in a million, which may not be as significant as first suggested.

To assess reports where the results might at first glance appear to be either very good or extremely concerning, the NHS has developed a section of its website called Behind the Headlines (www.nhs.uk) which regularly explains and dispels some of the misconceptions often reported in the media. The site, which you can find within the NHS Choices section, provides other useful information and general non-biased advice.

Managing editor

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COVER PHOTO:

Hiding in the circus. An abstract image of a woman's face.

Aggressive treatment of psoriatic arthritis results in 'significant' improvement, says new research.

People with a type of arthritis affecting the skin and joints respond significantly better to early, aggressive drug treatment compared to standard care, according to preliminary results presented by a University of Leeds lecturer to a major conference in America.

Dr Philip Helliwell, who is leading an Arthritis Research UK-funded multi-centre clinical trial into psoriatic arthritis, revealed at the prestigious American College of Rheumatology Congress in San Diego that patients benefited from a rapid escalation of medication.

Although better drugs are now available to treat the condition than in the past, Dr Helliwell and his team believe that earlier, intensive treatment of the condition can reduce joint damage more effectively, preventing disability.

"We have found that tight control of disease activity in psoriatic arthritis, using a targeted approach, significantly improves the joint and skin outcomes for newly diagnosed patients with no unexpected side-effects," said Dr Helliwell, senior lecturer in rheumatology and a leading UK authority in psoriatic arthritis.

Dr Helliwell and his colleague Dr Laura Coates from the Leeds Institute of Rheumatic and Musculoskeletal Medicine, spearheaded a £550,000 national clinical trial, involving more than 200 patients, based at Chapel Allerton Hospital in Leeds.

They compared intensive early treatment carried out in specialist clinics with the kind of care patients usually receive, to find out which group of patients does better over a year.

"We predicted that a tighter, more aggressive treatment of psoriatic arthritis in which patients are given escalating dosages of drugs if their condition is not responding, and who then see a specialist every month with the aim of controlling their symptoms fully and as soon as possible, would result in a good outcome after 12 months," explained Dr Helliwell.

"That has proven to be the case. These findings could have significant implications for the way that this common type of inflammatory arthritis is treated and controlled."

Earlier, intensive treatment of the condition can reduce joint damage more effectively, preventing disability

Medical director of Arthritis Research UK Professor Alan Silman said: "Patients with psoriatic arthritis in general have fewer affected joints than those with rheumatoid arthritis, but there are sub-groups of patients who suffer a very severe form with a significant risk of irreversible, joint damage.

"Research into this disorder has lagged behind rheumatoid arthritis research, although patients have similar levels of disability and reduction in quality of life. In addition, they have to cope with often very severe skin problems and arthritis affecting the spine.

"Our trial has shown that patients with psoriatic arthritis benefit from early aggressive treatment that reduces the inflammation in the joints. Such an approach proved successful in the treatment of rheumatoid arthritis and this research could lead to a similar change in the way psoriatic arthritis patients are managed in the future."

Source:

Leeds Institute of Rheumatic and Musculoskeletal Medicine

www.leeds.ac.uk

Psoriasis beyond the skin

There is further evidence emerging that psoriasis should no longer be considered just an affliction of the skin with a number of reports raising significant indication that other diseases are strongly associated with in particular the severer types of psoriasis.

A study published in the British Medical Journal (BMJ) in October found that moderate to severe psoriasis is associated with an increased risk of chronic kidney disease (CKD) independent of traditional risk factors, such as diabetes and heart disease.

The authors recommend closer monitoring for kidney problems in patients with 3% or more of their body surface area affected to help detect and treat signs early and suggest careful consideration of medications, which may cause kidney disease in this at-risk patient population.

Increasing evidence suggests that psoriasis is associated with diabetes and heart disease independent of traditional risk factors. Some doctors think psoriasis may also be associated with kidney disease but, so far, studies have been small and shown conflicting results.

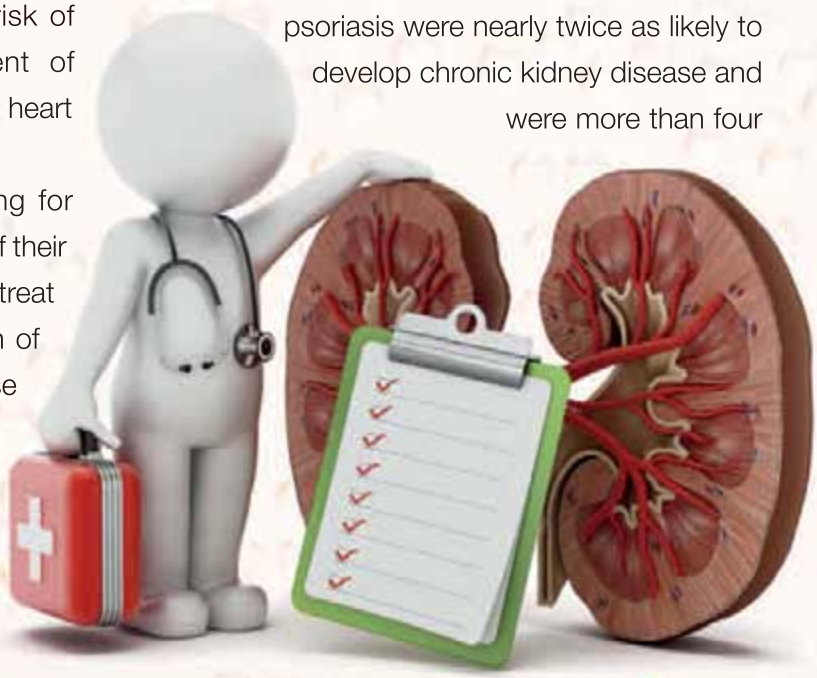
A team of researchers based in Philadelphia, USA, decided to compare the risk of chronic kidney disease in patients with and without psoriasis.

Using a UK primary care electronic medical records database (THIN), they identified 143,883 patients aged 18 to 90 years with psoriasis. These patients were matched with 689,702 patients without psoriasis who acted as controls. Patients with psoriasis who received phototherapy or oral or injectable (biologic) medications were defined as having severe disease.

The team then analysed how many of these patients had received a diagnosis of chronic kidney disease based on standard tests between 2003 and 2010.

Known risk factors for chronic kidney disease, such as age, sex, presence of diabetes, high blood pressure, high cholesterol levels, and use of NSAIDs were also taken into account.

The researchers found that patients with psoriasis, particularly those with severe disease, were at greater risk of developing moderate to advanced (stage 3 to 5) chronic kidney disease compared with control patients. Furthermore, those with severe psoriasis were nearly twice as likely to develop chronic kidney disease and were more than four



times as likely to develop end stage renal disease requiring dialysis.

After adjusting for known risk factors, severe psoriasis remained an independent risk factor for chronic kidney disease and end stage renal disease requiring dialysis.

A further analysis of 8,731 psoriasis patients with measurements of affected body surface area matched to 87,310 patients without psoriasis showed similar results - a greater risk of chronic kidney disease in patients with moderate and severe disease.

Mild psoriasis is defined as limited disease with 2% or less body surface area affected, moderate as scattered disease with 3%-10% body surface area

affected and severe as extensive disease with more than 10% body surface area affected.

The combined results indicate that, although no association is seen in patients with truly mild disease, associations are seen in moderate and severe psoriasis, which are estimated to affect over 20% of patients worldwide, say the authors.

They also point out that, although the relative risk was higher in younger patients, the absolute risk of chronic kidney disease attributable to psoriasis increases with age.

For example, in patients aged 40-50 with severe disease, psoriasis accounts for one extra case of chronic kidney disease per 134 patients per year, and in those aged 50-60, it accounts for one additional case per 62 patients per year, they explain.

"Future studies are warranted to confirm our findings, determine the mechanisms mediating renal insufficiency in psoriasis, and examine the impact of treatment for psoriasis on the risk of chronic kidney disease," they conclude.

'Known risk factors for chronic kidney disease, such as age, sex, presence of diabetes, high blood pressure, high cholesterol levels, and use of NSAIDs'

Other comorbidities

In another recent report published in the JAMA Dermatology (Journal of American Medical Association), the authors state that psoriasis is associated with higher rates of other diseases including chronic pulmonary disease, diabetes mellitus, mild liver disease and myocardial infarction (heart attack).

The researchers examined patient data from United Kingdom-based electronic medical records. Their analysis included 9,035 patients ages 25 to 64 years with psoriasis and 90,350 age- and practice-matched patients without psoriasis. Psoriasis severity was determined in 8,726 patients (96.6%), among whom 4,523 (51.8%) had mild, 3,122 (35.8%) had moderate and 1,081 (12.4%) had severe psoriasis.

Psoriasis overall was associated with a higher prevalence of chronic pulmonary disease, diabetes mellitus, diabetes with systemic complications, mild liver disease, myocardial infarction, peptic ulcer disease, peripheral vascular disease, kidney disease and rheumatologic disease, the study results indicate.

"The burdens of overall medical comorbidity and of specific comorbid diseases increase with increasing disease severity among patients with psoriasis. Physicians should be aware of these associations in providing comprehensive care to patients with psoriasis, especially those presenting with more severe disease," the authors conclude.

As mentioned in these reports, it is now time that psoriasis in its worse form is considered a serious disease, although with most people having milder disease a perspective has to be drawn between good appropriate medical care and scaremongering leading to anxiety.

Sources:
JAMA online: August 2013
The British Medical Journal: October 2013
www.bmj.com

New report calls for radical change for pharmacists

A new independent report urges a radical shift in the role of pharmacists towards improving care for those who need it most, reducing the need for costly and disruptive hospital treatment.

Now or Never: shaping pharmacy for the future envisages pharmacists across England expanding their role by treating many common illnesses, supporting people with long-term conditions and challenging wasteful, dangerous or inefficient use of medicines.

The authors warn that unless this shift takes place, the NHS will be letting down taxpayers and patients by missing opportunities to do more for less, and many community pharmacists risk being forced out of business as austerity and technological change drive down income.

The report, from the commission into future models of care delivered through Pharmacy chaired by Nuffield Trust director of policy Dr Judith Smith, finds that pharmacists have a marginalised position in the NHS and in health policy. It warns NHS England, the Department of Health and pharmacy leaders including the Royal Pharmaceutical Society that a united effort must be made to change this.

Dr Judith Smith, report author and chair of the commission said:

''The pharmacists I met during my work for this commission are demonstrating that their profession has far more to offer than the public or many people in the NHS understand. Yet all too often, their potential is going untapped, and this must change if the NHS is to be able to assure taxpayers that people are being supported to get the best use out of their medicines and pharmacies.

''With care for the frail elderly and emergency out-of-hours treatment at the top of the agenda, the door is open for pharmacists to secure a wider and important role in caring for patients. It won't be open for long, though, and only concerted and determined action from the profession itself can make sure that they don't find themselves shut out."

People across England should expect pharmacists to offer far more than just medicines. The report shows case studies of pharmacists providing vital health services ranging from vaccination to the management of anticoagulation for people at risk of stroke. In some areas, pharmacists are working with other health professionals to visit frail elderly people after they are discharged from hospital, helping them manage their conditions and keeping them from needing to go back into hospital.

The authors conclude that re-focusing pharmacists as caregivers could reduce demand on GPs, out-of-hours and hospital services, improve access and care for patients and free up capacity within these NHS services. This could play a major role in enabling the health service to cope with the unprecedented financial squeeze it faces, while still providing care free at the point of use, and improving access and dignity for patients.

They warn that pharmacists need to step up locally and

Radical changes for pharmacists

nationally to lead in improving the use of medicines and the NHS must be ready to take advantage of their expertise. It is unacceptable that while the NHS spends £12 billion a year on medicines, between 30% and 50% of patients do not take them as prescribed, and 6% of emergency admissions to hospital are caused by avoidable reactions to medicines.

Dr David Branford, chair of the Royal Pharmaceutical Society English Board said:

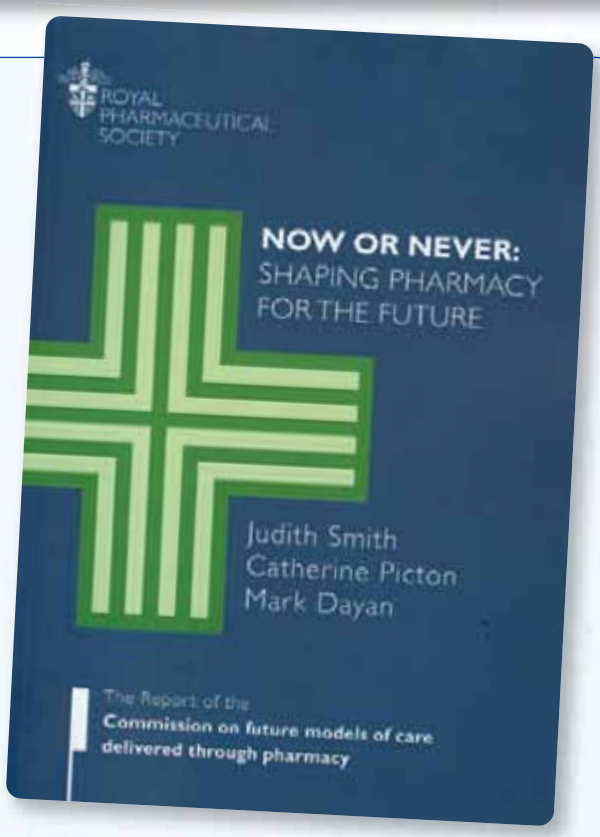
"Study after study has demonstrated that the best outcomes for patients and the safest use of medicines come when pharmacists and doctors work closely together as a part of a multidisciplinary team.

"As hospitals change and much of expert care moves beyond the hospital, pharmacists need to be a part of the core team looking after patients. Safer care will be enabled by better use of technology, allowing patients to share their care record with pharmacists.

"Pharmacists need to contribute to better care across all parts of the health service. Priorities are improving the care of people in care homes, supporting older people to stay well in their own homes and working alongside GP, nursing and social care colleagues to keep people safe and to improve health outcomes. I am certain the profession will rise to the clear challenge set out in this report."

The report's recommendations include:

- Pharmacists and their employers must shift their focus away from dispensing and supply of medicines towards providing a broader range of services
- They must drive change at a local level, proving to decision makers in the NHS and local government that they should be doing more
- The pharmacy profession should appreciate that there will be no new money: change will come from using existing funding better
- Pharmacists should work with other professionals in joint teams, and should come together in networks, or chambers like barristers, to provide large-scale new services
- The Department of Health (DH) and NHS England (NHSE) must include pharmacy in plans for the future of out-of-hours and urgent care, public health and the management of long-term conditions
- DH and NHSE should be open to pharmacists holding contracts individually or as groups rather than through employers, and should use their positions to shift funding from dispensing and supply towards new services



- DH and NHSE should work with pharmacy leaders to create a united narrative about the future of the profession
- The Royal Pharmaceutical Society and other groups representing pharmacy should take responsibility for making these changes happen, and should work in a coordinated way to improve professional leadership. This should include the creation of a leaders' forum where innovative pharmacists can spread and improve best practice.

About the Royal Pharmaceutical Society:

The Royal Pharmaceutical Society is the dedicated professional body for pharmacists. It was originally founded as The Pharmaceutical Society of Great Britain on April 15th 1841 by a group of leading London chemists and druggists. In 1988, The Queen agreed that the title 'Royal' should be granted to the Pharmaceutical Society. In 2010, it shed its regulatory function to become the new professional leadership body for pharmacists in England, Scotland and Wales.

For more information visit: www.rpharms.com

Confused? You will be

The NHS's patient information leaflets are "inaccurate, inconsistent, and confusing – and effort is duplicated" argues Dr Margaret McCartney, a general practitioner from Glasgow in a recent feature in the British Medical Journal (BMJ).

Dr McCartney said: "... the NHS is 'awash' with patient information and with many trusts commissioning leaflets from external companies and others writing their own, it is difficult to know how efficient and effective these leaflets are."

Previous studies have shown that leaflets are providing patients with inconsistent guidance and others are giving conflicting advice. As such, patients are being given very different information depending on where they live.

A study carried out on one set of leaflets for the removal of kidney stones found they did not consistently mention common complications and had a wide variation of information on drugs and painkillers. Furthermore, complications were often inadequately explained.

Sir Muir Gray, co-chair of the executive council of the Information Standard (a scheme for organisations producing evidence-based healthcare information for the public), said:

"It's a stupid system, a waste of money, and without rigorous standards the information is biased and misleading."

McCartney says that the problem of varying leaflets is not new: a BMJ investigation in 1998 found inaccuracies and outdated information in leaflets given out by general practitioners.

One researcher at the University of Oxford says the problem is that "the NHS still fails to take this seriously", adding that, at the moment, in most NHS trusts there is no one who has responsibility. This means that leaflets can end up amateurish "with the evidence and uncertainties not expressed clearly."

McCartney concluded that the challenge now is "to adopt high standards of updating information regularly and making it easily accessible." She added that "this is one area of the NHS where efficiency savings look ripe for the picking."

Editor's note:

PAPAA has been an Information Standard member since 2011, and abides by the principles of the scheme, which are to produce information that is

■ accurate ■ impartial ■ balanced ■ evidence-based ■ assessable and well written.

PAPAA is a leading supplier of information to the NHS and if you spot a clinic where the information is poor, lacking or of poor quality, please let us know and we will endeavour to provide our accredited information leaflets.

The Information Standard Certified member

We need your help

As part of The Information Standard scheme we have developed a patient user group to review all written material.
We are grateful to those members of PAPAA who have already agreed to carry out this role.

If you would like to get involved in reviewing our material then please get in touch.

For more information about the role and specification contact:
Caroline Marven on 01923 672837 or email cjm@papaa.org

Researcher questions the benefit of copper bracelets

For many people who live with arthritis any relief from pain is welcomed. A traditional remedy that people often turn to is the use of copper bracelets.

Researchers at the Department of Health Sciences at York, have carried out the first randomised controlled trial, to study the effects of copper bracelets and magnetic wrist straps for rheumatoid arthritis. Seventy patients with active symptoms each wore four different devices over a five-month period, reporting on their pain, disability, and medication use throughout the study. Participants also provided blood samples after wearing each device for five weeks, in order to monitor changes in inflammation.

According to new findings from the study, copper bracelets and magnet wrist straps have no real effect on pain, swelling, or disease progression in rheumatoid arthritis.

Dr Stewart Richmond, a research fellow in the Department of Health Sciences at York, who led the study, said:

''It's a shame that these devices don't seem to have any genuine benefit. They're so simple and generally safe to use. But what these findings do tell us is that people who suffer with rheumatoid arthritis may be better off saving their money, or spending it on other complementary interventions, such as dietary fish oils for example, which have far better evidence for effectiveness. Warning people who suspect they may have rheumatoid arthritis to consult their GP and seek early medical treatment, rather than placing faith in such devices, is also important in helping to avoid long-term joint damage resulting from uncontrolled inflammation.''

Dr Richmond suggests there are two main reasons why wearers sometimes report benefit:

''Firstly, devices such as these provide a placebo effect for users who believe in them; secondly, people normally begin wearing them during a flare-up period and then as their symptoms subside naturally over time they confuse this with a therapeutic effect. Pain varies greatly over time in conditions like rheumatoid arthritis, and the way we perceive pain can be altered significantly by the power of the mind.''

The paper 'Copper bracelets and magnetic wrist straps for rheumatoid arthritis – analgesic and anti-inflammatory effects: a randomised double-blind placebo controlled crossover trial' is published in **PLOS ONE at http://dx.plos.org/10.1371/journal.pone.0071529**

Source:

The Department of Health Sciences at the University of York

16 September 2013

www.york.ac.uk/healthsciences/

A review of selected published literature regarding how psoriasis affects mental functioning, social life, relationships and career

What can be assumed?

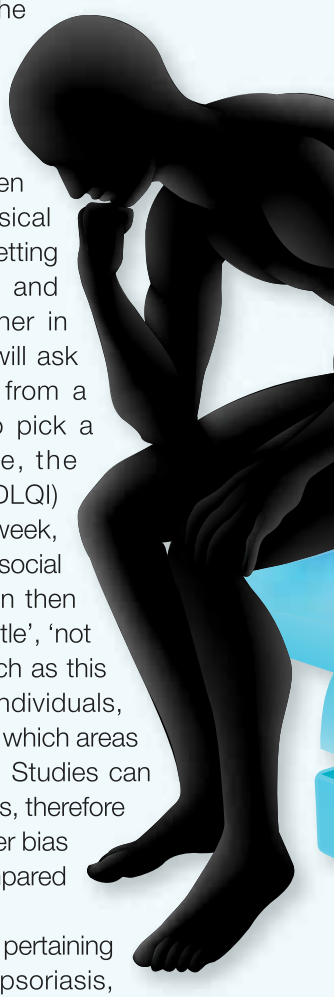
As psoriasis is a visible condition, it understandably affects many areas of life. Media influence has ingrained an idea that a perfect appearance is the most important aspect of a person, and that any defect is an object of ridicule. Therefore people with a condition such as psoriasis can feel angry, upset, regretful and socially stigmatised. Common sense dictates that such a condition would also impact an individual's social life, including sexual relationships, career, and participating in various activities.

Research has investigated the psychosocial impact of psoriasis, which refers to mental functioning, work life, relationships and social situations. Tools have been created to measure psoriasis impact on a person's quality of life in a quantifiable manner. Such tools also provide evidence to back up what can otherwise simply be seen as anecdotal evidence and common-sense conclusions.

Tools for measure

In the world of science, it is not enough to have simply a hunch about what psychosocial effect psoriasis will lead to. There needs to be development of instruments that measure its impact. Such tools have to be developed and tested for their reliability and validity. Reliability refers to the tool producing the same result when tested on the same person more than once. To be valid, a tool must measure what it sets out to, and not accidentally be measuring any other factors. Tools for measuring psoriasis impact can be applied through the questionnaires or interviews. The tools therefore, if reliable and valid, can be used to measure psoriasis impact on patients worldwide and the findings can be quantitatively analysed and reported.

The Psoriasis Area and Severity Index (PASI) is a tool used to calculate how severe a person's psoriasis is. The head, arms, trunk and legs are scored individually, and the four scores combine to give the final PASI score. If less than 10% of an area is involved, the grade scored is 1. Percentages then increase in intervals of 20 (10%-29%, 30%-49%...), with the grades increasing by one each time. Psoriasis is then further classified into one of three categories: mild (less than 3% of body affected), moderate (3%-10% of body affected), and severe (more than 10% of body affected). Using these classification groups allows for clinicians and researchers to have a basis for classifying psoriasis that all understand and use, and that always leads to a person being put into the same category no matter who diagnoses and classifies their psoriasis.



In order to assess how psoriasis affects quality of life, tools have been developed that look at the physical aspects of life e.g. getting up and getting dressed, work life, mental health, and social life. These measures, whether in interview or questionnaire format, will ask questions that require an answer from a choice of available answers, or to pick a number on a scale. For example, the Dermatology Life Quality Index (DLQI) includes the question 'Over the last week, how much has your skin affected any social or leisure activities?' The patient can then answer either 'very much', 'a lot', 'a little', 'not at all' or 'not relevant'. With data such as this collected from a large number of individuals, analysis can be performed to find out which areas and by how much psoriasis affects. Studies can also be replicated using the same tools, therefore eradicating the possibility of researcher bias and allowing results to be directly compared against once another.

The focus of this report is four areas pertaining to the psychosocial burden of psoriasis, reporting on studies into each area.

Depression and self-harm and suicidal ideation

Depression, unfortunately, is a taboo subject in today's society. No matter how hard charities and organisations try, there is still an idea that depressed people simply need to 'cheer up' or 'get over it'. The word is often used very lightly whereby people confuse simply being upset for a few days over a failed exam as being depressed. With all the stigma and confusion surrounding depression, it is not surprising that it is hard to recognise and diagnose in people. Some people do not seek the help they need due

to the social stigma. Symptoms of being depressed include constant tiredness, a loss of interest in previously enjoyed activities and poor appetite, sleeping pattern and sex drive. It seems logical to assume that a condition which affects the body's physical appearance has an effect on the mind.

A study which surveyed 217 psoriasis patients (of which 138 were inpatients and 79 were outpatients) used the Carroll Rating Scale for Depression (CRSD). The CRSD is a 52-item scale found to have high reliability and validity in screening for depression. The items include statements where respondents answer 'Yes' or 'No' referring to areas such as sleep difficulties, hopelessness, appetite changes, and suicide ideation. A score greater than 10 is used to screen for clinical depression presence. Compared to the other dermatology groups studies (acne patients, alopecia [hair loss], and atopic dermatitis [a type of eczema]), psoriasis inpatients with 52% (plus or minus 23.4%) of their skin affected had the highest depression scores. There was a 7.2% prevalence of suicide ideation, that is the respondent had answered 'Yes' to the item 'I have been thinking about trying to kill myself', among inpatients with psoriasis. This percentage decreased to 5.5% when the psoriasis outpatient scores were combined with the inpatient scores. However, the percentage for prevalence of suicide ideation in psoriasis patients is higher than that of any other the other dermatology groups examined in this study.

A review paper, which looks at the results by many studies that investigate the same area, found that there is a range between 10% and 62% for reported rates of depression amongst psoriasis patients. The review cites a finding by Schmitt and Ford that out of 265 psoriasis patients, 32% screened positive for depression. The PASI has been found to be an unreliable predictor of risk for depression, and therefore it is important to screen psoriasis patients no matter how their psoriasis ranks on the PASI.

Physicians have found that factors associated with anxiety are those that relate to quality of life (QOL), and QOL is often a stronger predictor of psychiatric morbidity than severity of psoriasis. The coping methods of focusing on emotion by venting feelings and avoiding situations that induce feelings of anxiousness may in fact cause anxiety themselves. Anxiety scores correlate with areas of visible psoriasis plaques, however a correlation does not imply causation, and it is unclear here whether psoriasis flares are causing anxiety, anxiety is causing psoriasis to flare, or whether both occur. Depression has been linked to psoriasis in a study using the Beck Depression Inventory (BDI), where a score of less than 9 indicates lack of depression, 10-17 mild to moderate and greater than 18 severe. The higher the score on the BDI, the greater the risk the patient had of their psoriasis flaring up.

Self-harm can occur in many ways, and not just those that are deliberate such as using sharp objects to make cuts to the body. Drugs such as alcohol and cigarettes are culturally well known to act as both rewards and commiserations for events and feelings. In those faced with the challenges of a psoriasis diagnosis cigarettes and alcohol can be perceived as stress relievers. However, smoking and alcohol consumption have been found to have negative effects related to psoriasis.

A study looking at women with psoriasis found smoking to be associated with psoriasis, and alcohol to be a factor that worsened existing psoriasis. Therefore, these methods that are an attempt to cope with psoriasis can lead to psoriasis and greater psoriasis severity. Smith and Fenske found alcohol exacerbated psoriasis. Young and middle-aged men with psoriasis were found to drink on average twice the amount of alcohol per week that non-psoriatics did, prior to the onset of their psoriasis. In a study of 95 psoriasis patients, 20% were found to have a problem with alcohol as defined by CAGE have you ever 'cut down', been 'annoyed' with criticism of your drinking, felt 'guilty' about drinking or had an 'eye-opener'? Alcohol as a coping mechanism is further shown to be destructive by Vincenti and Blunden who found that alcohol had an adverse affect on psoriasis treatment outcomes, particularly in males. There is also an increased risk of death secondary to alcohol consumption in people with psoriasis.

Education (with a focus on bullying in schools)

School years are often filled with self-consciousness, trying to fit in with the popular crowd, a desire to appear 'cool' and to form relationships. It is therefore understandable that a visual condition of the skin is going to be a target for bullies. It is common knowledge that bullies tend to target individuals who possess a feature or quality that is different from the norm. As psoriasis is a relatively rare condition and its appearance is visually

unappealing to some. It seems logical to conclude that children with psoriasis are subject to teasing and/or bullying by their classmates.

An Australian study used interviews to discover the experience with bullying of people with skin disorders. Twenty-nine of the interviewed patients had a diagnosis of psoriasis. The age range of the participants in the entire study was 13-73. Teasing was found to be common, and instances where teasing was so hurtful it led to psychological problems, this incidence was experienced in childhood or adolescence. The data from patients was then analysed thematically. Common themes that emerged were the negative nature of the teasing, teasing acting as an instrument to socially exclude, and teasing as a means of establishing power. Psoriasis patients expressed that a lot of the teasing come from the misconception that psoriasis is contagious. One female patient spoke of how insensitive the teasing was whereby people would outright ask what she had on her elbows or tell her they found her psoriasis revolting.

In stories of living with their psoriasis, many young people have expressed that they stopped doing P.E. and/or swimming due to being embarrassed about showing more of their body than usual, and being left out.

Occupation

As psoriasis has both physical and psychological impact, it is reasonable to assume that work life and opportunity are not free from its burden. Kruger et al found that 17% of psoriatics aged 17-54 reported they had experienced psychological effects in the workplace due to their disease. For those with severe psoriasis, 6% reported being discriminated against in their workplace. Twenty-three per cent of individuals in another study reported that their choice of career had been affected by their psoriasis.

Psoriasis can cause such pain and discomfort that work days are missed, and often patients have appointments with medical professionals. Psoriasis was found to account for between 2.3 and 26 work days lost per year per patient.

For some, the burden stretches to not being able to find employment. Fortune et al found a lower rate of employment in the UK for people with psoriasis compared to the general population. More than 50% of 369 patients with severe psoriasis were unemployed (with 26% retired). Thirty-four per cent of this group cited psoriasis as the reason they were not working.

Fleischer et al devised a hypothesis that the effect of psoriasis on work life might lead to a reduced socioeconomic status, which in turn makes obtaining psoriasis treatments difficult. A telephone survey by Kruger et al carried out in the US found that 42% of those with severe psoriasis with an annual income of less than $30,000 (£20,000) experienced financial distress due to their psoriasis.

Other social areas affected by psoriasis

Due to psoriasis not looking visually appealing and its tendency to sometimes itch, many people reported having to change their daily routine. Some have said they avoid certain social situations. Routines changed included bathing, dressing, rest, work, sleep, and intimacy. Over 26% of psoriatics reported having to change their daily routine regularly due to their condition. Forty per cent of those surveyed by the American National Psoriasis Foundation said that choosing comfortable clothing was the most difficult daily task that was influenced by psoriasis.

Ginsberg and Link found that 19% of their surveyed sample with mild to severe psoriasis had had a personal experience of social rejection. This included such incidences as being asked to leave the hairdressers, a gym, or a pool. Due to this, people tended to avoid situations where this might occur, as they believe the social rejection might reoccur.

Studies looking at the impact of psoriasis on family life and relationships found that there was increased pressure on family members of those with psoriasis. They felt they needed to spend extra time cleaning, had on occasion felt disruption to their own social life due to embarrassment/giving time to the psoriasis relative for care. Thirty-seven per cent of surveyed family members reported deterioration in their relationship with the individual with 8% reporting psoriasis had no effect on their relationship at all. Sampogna et al found that out of 936 psoriasis patients, 35.5% had experienced sexual impairment due to psoriasis e.g. feeling unattractive/ sexual activity being too painful due to psoriasis in the groin area.

What needs to happen in the medical world?

The articles used to write the previous sections unanimously claim that there needs to be more recognition by physicians of psoriasis as more than just a skin

condition. It also needs to be recognised that psoriasis severity is not a reliable measure to indicate how the quality of life of an individual is affected. Very mild psoriasis can give a person as much or even more of a psychosocial burden than the burden someone with severe psoriasis suffers. Further research could continue to look at areas of life psoriasis affects, how so, and what can be done to lessen its adverse effects.

About the author:

Tara Fletcher is a student studying for her BSc psychology at University of Hertfordshire. She has just completed a 120-hour second year placement at the Psoriasis and Psoriatic Arthritis Alliance (PAPAA). During her time at PAPAA she completed a paper on how psoriasis affects psychological and social aspects of patient life. Her interests include social and evolutionary psychology, with a particular interest on suppression of stereotypes and terror management. She also enjoys studying the importance of the doctor-patient relationship through shared decision-making. Additionally she enjoys statistics, and hopes to use her interests in her future psychological career.

Useful resources

PAPAA - There is a plethora of resources available to help with both understanding and treating psoriasis at www.papaa.org

Electronic Targeted Intervention for Psoriasis - eTIPs: www.etips.org.uk

Anti-bullying alliance: www.anti-bullyingalliance.org

Drink-aware: www.drinkaware.co.uk

Stopping smoking: www.quit.org.uk

NHS choices: www.nhs.uk

A full list of the literature examined for this report are available on request of by visiting: www.papaa.org

The Medicines and Healthcare products Regulatory Agency (MHRA) reported that people with serious underlying heart conditions, such as heart failure, heart disease, circulatory problems or a previous heart attack or stroke, should no longer use diclofenac.

This follows the completion of a European review, which found a small increased risk of heart attack and stroke.

Diclofenac is a type of non-steroidal anti-inflammatory drug (NSAID). Anti-inflammatory drugs are widely used and important medicines in the treatment of arthritis and many other painful conditions, including headache, fever and minor ailments. Diclofenac, along with ibuprofen and naproxen, is among the most widely used anti-inflammatory medicines in the UK.

Dr Sarah Branch, deputy director of the MHRA's Vigilance and Risk Management of Medicines Division said:

"Whilst this is a known risk and warnings have been included in patient and healthcare information for some time, this advice is now being updated.

"For many people diclofenac will continue to provide safe and effective pain relief but is no longer suitable for certain at-risk groups.

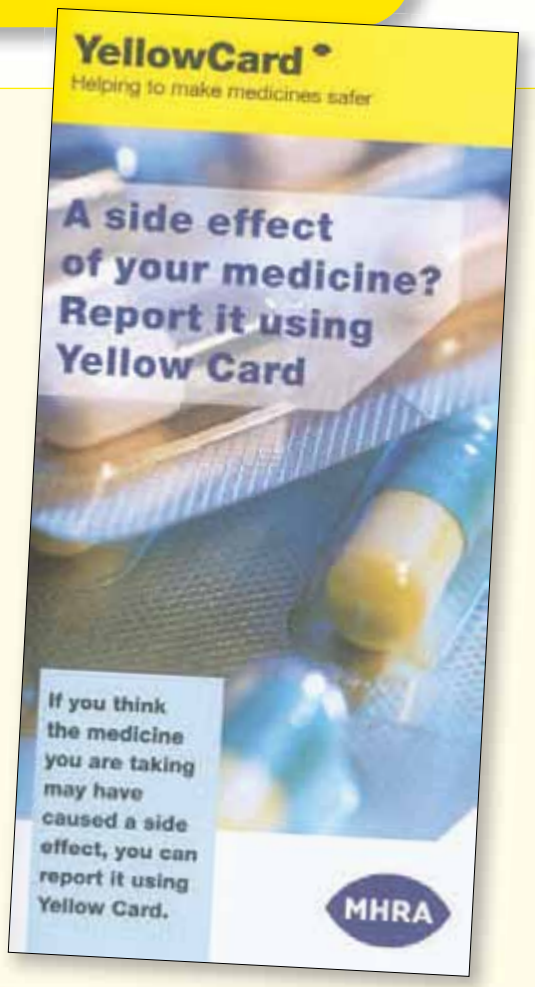
"Those with underlying heart conditions currently taking diclofenac should speak to their doctor or pharmacist at their next routine visit to consider an alternative pain relief treatment.

"People with certain cardiovascular risk factors such as high blood pressure, raised cholesterol, diabetes and smoking should only use diclofenac after careful consideration with their doctor or pharmacist."

If you are concerned about any medication you are taking please talk to your doctor or pharmacist.

The Yellow Card Scheme

If you suspect that you have had a side effect to your medicine, you can inform the MHRA via the Yellow Card Scheme. Ask your pharmacist for a Yellow Card or better still report it online.



www.yellowcard.gov.uk

About the MHRA

The MHRA is responsible for regulating all medicines and medical devices in the UK by ensuring they work and are acceptably safe. Underpinning all their work lie robust and fact-based judgements to ensure that the benefits justify any risks. The MHRA is a centre of the Medicines and Healthcare Products Regulatory Agency, which also includes the National Institute for Biological Standards and Control (NIBSC) and the Clinical Practice Research Datalink (CPRD).
The MHRA is an executive agency of the Department of Health.

For more information visit: www.mhra.gov.uk

Impact of new drug driving law

Recent proposed legislation in England and Wales has attempted to provide new clarity to the offence of driving whilst under the influence of drugs. The law primarily aims to take a tougher line on the use of any of the following eight illegal drugs; cannabis, ecstasy, cocaine, ketamine, benzoylecgonine (primary metabolite of cocaine), methamphetamine, LSD and 6-monoacetylmorphine (heroin and diamorphine). The law also includes ways to deal with drivers who use specific prescribed drugs. The list of legal controlled drugs which will be subject to the law are clonazepam, diazepam, flunitrazepam, lorazepam, methadone, morphine, oxazepam and temazepam, with higher limits set for these drugs.

Roads minister Stephen Hammond said: "We know that the vast majority of people who use these drugs are doing so responsibly and safely and that is why our approach does not unduly penalise drivers who have taken properly prescribed medicines.

"Together, these proposals will make our roads safer for everyone by making it easier for the police to tackle those who drive after taking illegal drugs and clarifying the position for those who take medication."

The limits proposed follow the recommendations of an expert panel, which in the vast majority of cases will prevent the new offence catching out drivers who have taken properly prescribed or supplied drugs in accordance with the directions of a healthcare professional or the drug manufacturer. This will avoid inconveniencing the public and taking up police time.

There is one further controlled drug, amphetamine, which has some medical use in specific circumstances, but which is often taken illegally and which the government proposes to include in the regulations.

If you are concerned about any drugs or medication you take and the effect they might have on your ability to drive, talk to your healthcare provider.

New prescribing legislation

New legislation has been introduced that allows physiotherapists and podiatrists in the UK to independently prescribe medication to their patients.

The new legislation, which came into force in August 2013, means that physiotherapists and podiatrists in the UK are the first to be able to independently prescribe medication to their patients.

The move means patients will no longer have to go back to their doctors to get medication after visiting the physiotherapist or podiatrist, freeing up valuable time for GPs and making things more convenient for the patient.

Around 15 million people are currently living with a long-term condition which requires trips to hospital or to the GP. Many of these people will benefit from being treated closer to home and in a more timely manner, enabling them to better manage their condition.

Advanced practitioners will have to complete a training course approved by the Health and Care Professions Council and will only be able to prescribe medicines relevant to their role.

The full impact of these changes will be felt in summer 2014, when practitioners have completed their courses and are starting to prescribe for their patients.

Care and support minister Norman Lamb said:

''This change will not only benefit patients by making it more convenient to get treatment but it will also free up valuable GP time. We are showing the world that the NHS is at the forefront of healthcare, paving the way for other countries.

''Physiotherapists and podiatrists are highly skilled professionals and these changes will allow them to give better care to the millions of people with acute and long-term conditions.''

The development will improve timely access to medicines whilst delivering care closer to home and support people to remain in and return to work and enable self-care and self-management of condition which improve treatment results for patients by maximising the benefits of physiotherapy and podiatry.

For example, podiatrists, who treat patients with a wide range of conditions including diabetic foot ulcers and arthritic disorders in the foot and ankle, are able to prescribe medication, promptly.

Physiotherapists are able to prescribe medicines for symptoms such as pain and inflammation. The opportunity to prescribe pain relief and other medicines will help many patients to respond more quickly to their treatment.

Phil Gray, chief executive of the Chartered Society of Physiotherapy, said:

''This is a landmark moment that will lead to patients receiving faster, more effective treatment for their condition.

''Physiotherapists being able to independently prescribe – for the first time anywhere in the world – will remove bureaucracy, free up time for doctors and save money for the NHS.

''But the most important impact of this new responsibility will be seen in the quality of care patients receive.

''Patients will be able to access pain relief and other medication quicker and this should help them get greater benefit from their physiotherapy. It is good news for patients and an important step forward for the NHS.''

Joanna Brown, chief executive of the College of Podiatry said:

''The new legislation will provide patients with more prompt and better access to treatment, helping to integrate care and reduce the pressure on other health care professionals. Podiatrists play a key role in the management of conditions such as diabetes, arthritis of the foot and ankle and dermatological conditions of the feet. The ability to independently prescribe will particularly benefit patients in these areas.''

Not all physiotherapists and podiatrists will be eligible to prescribe medications. It will be for those who meet the criteria and have successfully completed the approved education programmes. These people will then be annotated as an independent prescriber on the relevant Health and Care Professions Council register, which will then enable them to independently prescribe.

Karen Middleton, chief allied health professions officer at NHS England said:

''This is a huge step for both the physiotherapy and podiatry professions in terms of being able to provide services which offer patients better access, a better experience and improved outcomes. It may also reduce cost. Physiotherapists and podiatrists need to influence local commissioners in terms of how these new prescribing rights can result in significant service redesign, in particular in order to reduce the demand on GP time. I would like to thank all those who have collaborated with us on this work.''

Source:
Department of Health
20 August 2013

Psoriasis in Practice

A new Psoriasis in Practice taster course for healthcare professionals has been developed to offer potential students the opportunity to preview some of the content of the full e-learning programme. Healthcare professionals can register for the 7-day taster course via www.psoriasisinpractice.org.

Psoriasis in Practice e-Learning Programme

Psoriasis in Practice is a web-based continuing professional development course for primary care health professionals who are interested in expanding their chronic disease management knowledge to include psoriasis and psoriatic arthritis.

Background

Development of the course by Aneurin Bevan Health Board's Academic Dermatology Unit and funded by the Psoriasis and Psoriatic Arthritis Alliance (PAPAA) encompasses a practical, self-paced interactive course, with a patient-centred approach to psoriasis and psoriatic arthritis education for the primary care nurse.

Course aims

The 12-week programme has been developed to improve the knowledge of healthcare professionals in primary care in order to improve the health outcomes of people with psoriatic disease. Case studies and patient interviews illustrate the impact of psoriasis and psoriatic arthritis on the individual. The course also focuses on the aetiology and treatments for psoriasis and psoriatic arthritis, and the comprehensive nursing assessment and management tools that will help the healthcare professional support their patients' primary and secondary care treatment.

Educational support

Dermatology clinical nurse specialists will support the students as they progress through this self-directed programme of evidence-based educational resources. Coursework will involve self-assessments and students are encouraged to reflect on their own practice in the form of short, written assignments which will be assessed and graded by the tutor. On successful completion, a certificate of completion with Continuing Professional Development endorsement from the University of South Wales will be awarded.

What previous participants have said ...

"... We have updated existing care-plans to include a more detailed skin assessment (not just pressure ulcers and wounds), added a PsA chart for all psoriasis patients, identified undiagnosed psoriasis patients, updated our pre-admission form, updated care staff training, developed a skin infection care plan, etc. The impact in our area and on my practice has been immense. The GP who was my mentor has also returned and updated the surgery computer system to include best practice on requesting bloods, and current product information + best practice from me. ..."

"...I have really enjoyed this course. The course content is pitched at the right level, very informative and nicely challenging. I very much liked the fact that the course content is broken into sections with three 250 word assignments and all online and distance learning so I could fit the studying in around my workload. ..."

"... This course has helped to enhance my knowledge of psoriasis and given me a greater understanding of patient experience and where I could offer more support. The knowledge gained on psoriatic arthritis has been invaluable and from this I will include a joint assessment in our nursing practice with onward referral where necessary. ..."

"... I have learnt when to use treatments and advise on basic emollients, have some knowledge on steroid topical treatments which I will start advising supported by the GP. I have also realised how much psoriasis and psoriatic arthritis affects the patient and the impact on their lives. This will enable me to be more empathetic and supportive to them. I am now aware of secondary care options and hope to build on my knowledge and possibly support the GP who deals with dermatology clinics. ..."

"... I have learnt a lot about the management and indication of psoriasis. I feel confident in the mapping process of psoriasis and the types of treatment available. I really enjoyed the course and would like to be informed of any further e-learning available. ..."

To find out more, and register for a FREE taster version of Psoriasis in Practice for healthcare professionals

Web: www.psoriasisinpractice.org

Twitter: @PsoriasisPiP

Writings on the wall

A selection taken from our Facebook page at www.facebook.com/papaa.org

What makes living with psoriasis and or psoriatic arthritis so difficult? I guess each of us will have a different view; is it the overwhelming burden of coping with treatments that even if they work (or don't) are still horrible? Or the new carrier bag of hope, which contains the next answer, that will resolve it? The time wasted in isolated loneliness applying foul unpractical creams and ointments? The dwindling eagerness on day 42, week 6 and dissolution that yet another treatment fails to meet our expectations?

How about that sudden awkward silence in the hairdressers, and the sly glance in the reflection, when you wait for the question (that often doesn't come), but are ready to say the answer "It's only psoriasis", as though that statement will wipe away the expression of horror you have witnessed in the mirror? Then there is the trail we leave behind; we could say that we are literally everywhere.

What about the pain and stiffness first thing in the morning with psoriatic arthritis? Or that sense of tiredness and fuzzy head that just doesn't go away? How about the cups or glasses that have been dropped when your brain and grip just don't want to play nicely? Then the days of complete and utter desolation of being inflicted with not one life-long problem but two, with the question *why me*?

The ever-present state of being a psoriatic is not just for one day a year, but a 7 days a week, 365 days a year, a lifetime of coping. It is true the lows are very low sometimes, but to those that love and care for us, our wives, husbands, children and friends, we are more than just psoriatics; we are people who just happen to have something extra. Let us not be defined by our disease, but learn to live with it. Trying to change the world in one day is a huge task, changing how we deal with the world day-to-day is a lot easier.

I have learned to live with psoriasis and psoriatic arthritis. Be positive and take control.

"I have had psoriatic arthritis for 33 years and have grown up with it. I too have adopted the be positive and take control attitude. I've come to learn that what is harder is to recognise those battles you can't win. They are not failures on your part but acceptance that compromise can sometimes be better for you than fighting a losing battle. PsA can change the way your body works but it'll never change the person you are - unless you allow it to."

" I'm new to all this. I have been searching for answers for years. Sick of being told "it's because you are overweight", "you are just menopausal" etc. etc. Three doses of methotrexate and I am starting to see that there is a future that doesn't involve me curling up in a ball and giving up."

" I recognize myself in what you've written. I'm in about the same position and right now I'm angry, sad and peed off by doctors telling me I should change my life situation, don't stress, blah, blah... I take some ibuprofen, which doesn't make any difference. Waiting for an appointment with the rheumatologist to hopefully get some help.... I am 57 and there is still much life left which I want to spend without pain..."

"Only diagnosed 18 months ago but suffered from the symptoms for a lot longer. Time helps make things easier to deal with but some days are still worse than others and it does help to have a moan from time to time. The support that is available really does help and along with family support you can stay positive and take control - I'm so lucky to have that support and it keeps me going despite all of the things mentioned above and more..."

" I got PsA after having my twins 18 years ago. Took ten years to get correct diagnoses, have just adapted lifestyle around it. Main thing that gets me down is I can't walk for more than ten mins as mainly my knees and lower back have arthritis, and sometimes pain unbearable but when I feel down and low I think of people worse than me that can't walk at all or who are dying; at least I'm alive and have the love of my husband and kids."

"Excellent post, perfectly put. Keep telling it exactly how it is!"

" It's a daily struggle and some days are worse than others but you get used to the pain & fatigue. If it wasn't for all the medication and a miraculous hip replacement I wouldn't be able to work or get out & about"

"... actually filling up reading some of these posts. I was diagnosed with PsA nearly 3yrs ago, I run a support group for unpaid carers finding information and help for them but took until about 5mins ago before it crossed my mind to look for something for ME. Can identify so well with a lot of the statements, about the pain, the tiredness, constant changing of medication to find something that gets you through the day, being told it's your weight (although having lost nearly 7.5 stone I can say it got me out of the wheelchair and onto sticks for a while), the sleepless nights lying awake with eyes closed followed by the nausea and vomiting from meds through lack of sleep, 5 days in bed after walking around on my honeymoon, the depression from losing my job and feeling useless but the feeling of love and support I get from my husband and family are priceless. So glad I found this Facebook page..."

" So true. When I started having seizures at 12, I did not ask *why me*? But it did take about 3 years to accept the medicine regime necessary to lead a normal life. When I started having symptoms of endometriosis and infertility in my early-mid 20s, again I did not ask Why me? But it did take over 10 years to seek surgical help and finally have the child we love.

But when my feet started swelling and cracking, and I started falling asleep at my desk, and it felt like a bee was roaming my body trying to find a joint to settle on, too exhausted to drive in the morning, or walk due to hip and foot pain, and nails growing funny, and toes become deformed, and when finally I had to stop my favorite activity – running ... then I said *why me*? And it took a few years to finally embrace this and slow down, take more meds, and learn how to pace myself...and life is getting better.

Ok. I did cry and say *why me*? for each chronic illness, but the continued fatigue and exhaustion is, well, exhausting!

Love my family and friends for being there still today. Life is good."

" Thank you, well said. Could have been me writing this. Still struggling over 2 years later to accept diagnosis. Like the positivity, honestly lovely to hear it put so plainly what I identify with as my daily struggle too. Hard not to get frustrated with the compromises I have to make with myself but am learning"

"... had psorasis since was 10; only in last 18 mths did I notice the bone fatigue, extreme tiredness and the pain in joints. Finally got the truth of having PsA; which is a relief that i got a name for it. Been taking methotrexate for nearly 16 mths and so far all blood tests are clear. Lost some weight, do yoga and pilates but accept that some days I still need 20 hrs a day of sleep. Have become more proactive with my health though. Funny thing is that I probably had PsA for yrs."

"I keep positive and use treatment when I remember, I only have psoriasis ... and I always use special shampoo, I think it's your body's way of dealing with stress, I don't know."

"I have it too, and understand well all that you have outlined. I am in my sixties now and have also learned to live with it. It doesn't mean I don't moan about it from time to time."

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

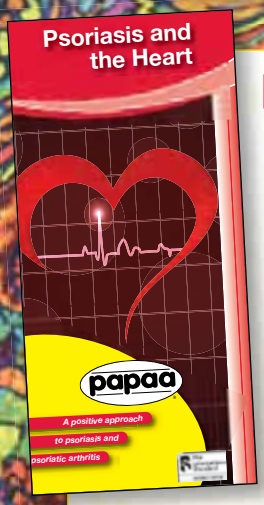
Visit the PAPAA Facebook page and read what other people are talking about. You can access the PAPAA page by clicking the link from our website home page.

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 then you can follow us by clicking the link, which is also located on our home page www.twitter.com/PsoriasisInfo

Marketplace

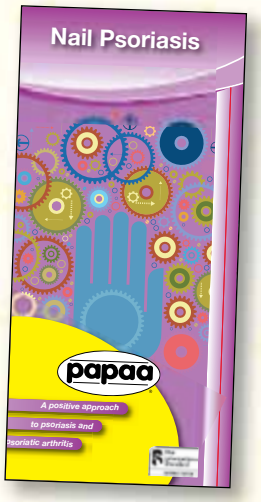


New fully revised and updated leaflets

In our continual support of the Information Standard scheme, we have been updating our complete range of leaflets.

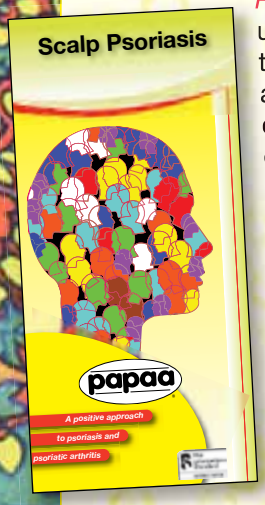
Psoriasis and the Heart was reviewed and revised by Dr Helen S Young, senior lecturer and honorary consultant in dermatology at the University of Manchester. Dr Young wrote the original leaflet in 2008 and we are grateful to her for this full revision and review.

The content covers the psoriasis-heart connection and includes what you can change, what you cannot, recognising the warning signs and taking action to help reduce risk.



Another review was one of our most popular leaflets called *Nail Psoriasis*. The leaflet was reviewed and revised by Dr David de Berker, consultant dermatologist and honorary clinical senior lecture at the Bristol Dermatology Centre at the Bristol Royal Infirmary. Dr de Berker, has provided an expert view on what nail psoriasis is, what changes can occur in the nails, what can be done and provides you with some general tips on nail care.

Our most recently published reviewed leaflet is *Scalp Psoriasis*, which is designed to help you understand what scalp psoriasis is, what the symptoms are, what the treatments are and offers some useful tips for dealing with the condition. This revised edition was written by consultant nurse Karina Jackson of the St John's Institute of Dermatology, Guy's and St Thomas' NHS Foundation Trust in London. Karina provided an excellent revision and fully updated the content with a section on the latest psoriasis guidance as issued by the National Institute for Health and Care Excellence. We are grateful to Karina for her thorough and expert input.



All of our leaflets are assessed by our voluntary lay reviewers, who provide invaluable feedback and vital suggestions to help improve the language and readability. If you would like to become a reviewer further details can be found on page 8.

All our leaflets are available by post free of charge or can be downloaded from our website www.papaa.org

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.

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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.