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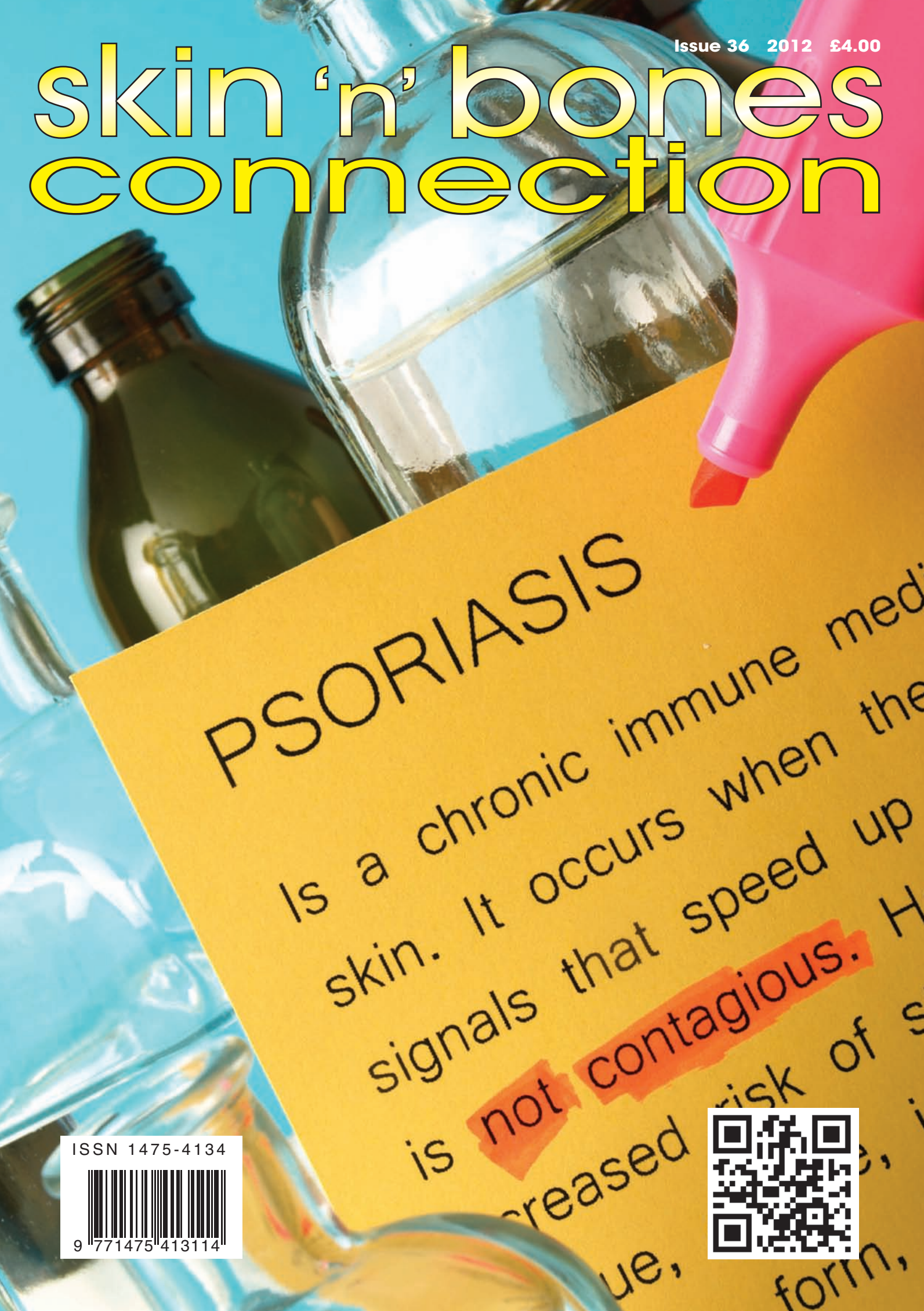
skin 'n' bones connection



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Correspondence Address:
PAPAA
PO Box 111, St Albans, Hertfordshire AL2 3JQ
E-mail: info@papaa.org
Web: www.papaa.org
Tel: 01923 672837 Fax: 01923 682606

Production team:
Julie Chandler
Managing Editor

Typesetting and Design
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Registered office: Acre House
11–15 William Road, London NW1 3ER

papaa

Dear Reader

The need for psoriasis and psoriatic arthritis to be recognised widely has been given a recent lift with the publication of the National Institute for Health and Clinical Excellence (NICE) psoriasis guideline (page 3). The publication of the guideline is a step in the right direction, but only if, adopted by healthcare providers. The next time you visit your doctor's surgery, you could ask your GP if he is aware of the guideline; if not, you might like to inform him that it contains important evidence based advice which will help you to manage your condition.

The requirement for evidence to demonstrate that what you are prescribed to treat your condition is safe and works is highlighted with a warning (page 7-8) from the Medicines and Healthcare Regulatory Agency (MHRA). The article is about the sale of an unlicensed and unproven treatment. It is very easy to be seduced by claims made, but always look for the evidence that those claims are backed up by good, robust clinical research. If a product sounds too good to be true, it probably is.

While on the subject of awareness, the more psoriasis and psoriatic arthritis are highlighted, the more likely symptoms will not be missed. Awareness can take many forms (page 13), so if you have ideas about ways to raise the profile of the conditions, please let us know.

Managing editor

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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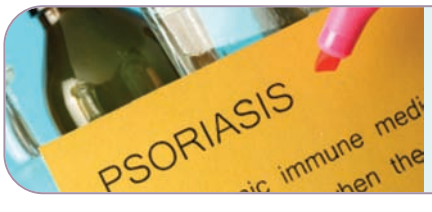
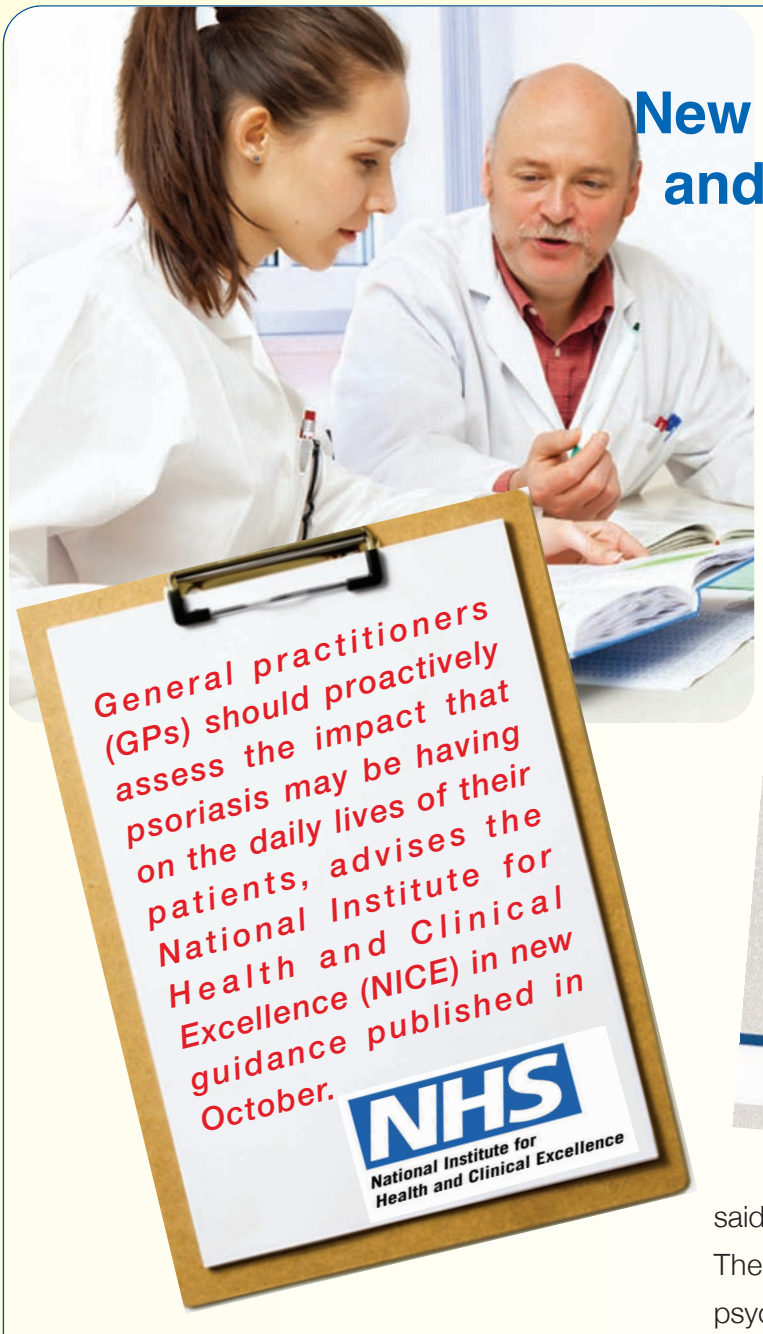
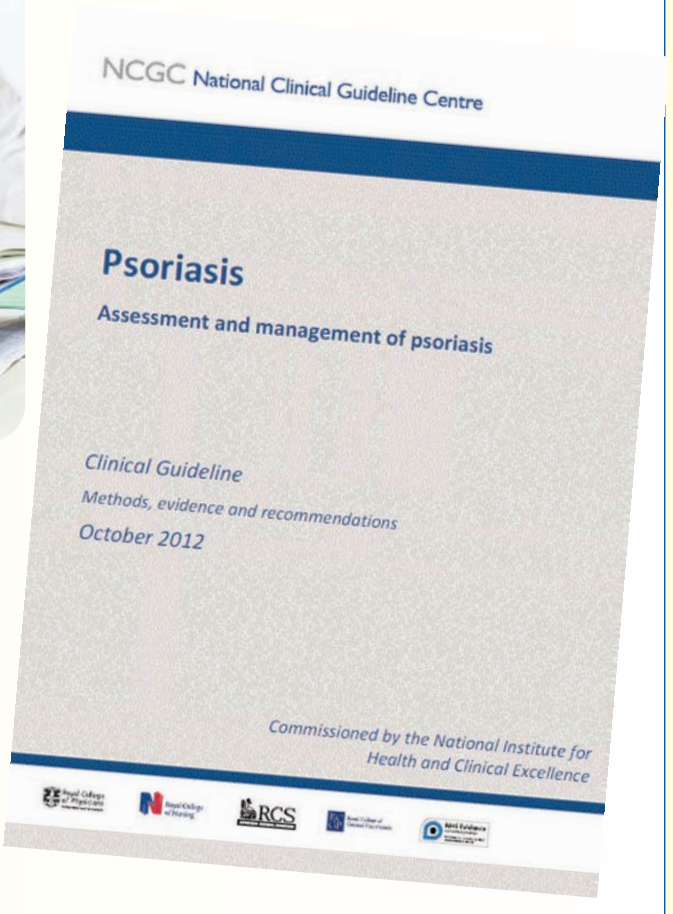


COVER PHOTO:

It's hard to believe that in the 21st century many people still think you can catch psoriasis. This incorrect belief demonstrates the need to keep highlighting that psoriasis is not contagious.

New psoriasis assessment and treatment guideline





In its first clinical guideline on the assessment and management of the condition, NICE advises GPs and other healthcare professionals to assess the impact that psoriasis has on the physical, psychological and social wellbeing of their patients. They should do this when they first see their patients, before they refer them to specialists, and when they monitor how they are responding to treatments.

Dr Catherine Smith, a consultant dermatologist who chaired the development of the NICE guideline, said: "Psoriasis is much more than a skin irritation. The condition can have profound functional, psychological and social effects on a person's life. It is vital that GPs and other healthcare professionals recognise these possible consequences when they first see their patients, and that they routinely assess the impact that the disease is having on their daily lives. Early and proactive identification will allow patients to receive the support and effective treatment they need in a timely manner. Importantly, accurate assessment of people with psoriasis will ensure they can access the right treatment as early as possible whether in primary or specialist care."

Also in its new clinical guideline, NICE advises that everyone with psoriasis should be assessed for

psoriatic arthritis on an annual basis, particularly during the first ten years, as this is when the condition is most likely to develop.

Around one in seven people who have psoriasis will develop psoriatic arthritis; early diagnosis is crucial and so annual assessments will allow those with actual or suspected psoriatic arthritis to be referred to specialists sooner.

"Psoriatic arthritis is rarely seen by GPs"

Dr Natasha Smeaton, a GP who helped develop the NICE guideline, said: "Psoriatic arthritis is rarely seen by GPs and so there may be confusion regarding how it should be diagnosed when compared to other joint problems, such as 'wear-and-tear' arthritis and gout. Early diagnosis is important because the condition is aggressive and associated with progressive joint damage. There are effective treatments available and so patients should receive these as soon as possible.

"The NICE guideline advises healthcare professionals to offer annual assessments for psoriatic arthritis to all of their patients who have psoriasis. They should use a validated tool in these assessments, such as the Psoriasis Epidemiological Screening Tool. This will facilitate more timely referrals to rheumatologists so that patients can receive the treatments they need."

The guideline is the first to be produced by NICE to help GPs and other healthcare professionals assess and treat their patients with this condition.

Professor Mark Baker, director of the centre for clinical practice at NICE, said: "Whilst there is no cure for psoriasis, treatments are effective and can include topical therapies, phototherapy and systemic medication, depending on the severity and extent of the disease.

"Clinical practice for the treatment of psoriasis is variable across the NHS. This guideline provides clear advice for the NHS on the assessment and management of psoriasis in order to improve comfort and minimise the effects of living with the condition."

SOURCE:
NICE press release 24 October 2012

About NICE

The National Institute for Health and Clinical Excellence (NICE) is the independent organisation responsible for providing national guidance and standards on the promotion of good health and the prevention and treatment of ill health.

The clinical guideline on the assessment and management of psoriasis is available at: www.nice.org.uk/CG153

http://www.nice.org.uk/patientsandpublic, has been given a permanent web link so that patients can bookmark it as their homepage for NICE guidance.

Bullying

A shocking 47% per cent of people with a skin disease in the UK have been victims of verbal abuse one or more times from another member of the public, a new snapshot survey reveals.

The online survey, conducted by the national skin disease research charity, the British Skin Foundation (BSF), also discovered that a further one in six (16%) people admitting to having self-harmed as a result of their skin disease. Disturbingly, seven people out of all those who took part said they had attempted suicide, with another 17% (125 respondents) stating they had contemplated suicide at some stage.

A total of 729 people were asked a series of questions relating to their skin disease or that of the person they care for. Questions were asked on the ways skin disease affects daily life, including forming sexual relations, social life and work life. The results show that the long-term effects of skin disease can have a devastating impact on sufferers' lives in ways few would expect.

Many skin diseases, such as vitiligo and psoriasis, can be very noticeable and visually striking, and likely to provoke a response from an untrained eye. Worryingly, a fifth of respondents described that they had been victim to regular bullying because of their condition, whilst one in every eight people who took part said they had suffered some form of physical abuse from another member of the public at least once.

Common conditions such as eczema and even acne, can affect people on a long-term basis. Asked to rank what they felt were the top three areas affected by their skin condition, 70% said a fall in self-confidence was their biggest issue, 42% said it impacted on their work and more than half (56%) said making friends was one of their biggest problems when it came to skin disease.

For many, sadly, having a skin disease had implications for their romantic and sexual relationships, with a fifth of participants (75 people) who answered that question stating that their skin disease was the driving factor for the breakdown of their most recent relationship or a previous one.

Living with a skin disease can prove to be a hugely stressful experience; a previous survey conducted by the BSF last year revealed that almost half of respondents suffered from sleep deprivation caused by severe pain and/or itching. Other factors that contributed to feelings of stress included sufferers feeling over-reliant on others for care, hospitalisation for treatment, and time off work or even unemployment. What's more, a study conducted in 2001 showed how acne, one of the most common skin diseases, affecting over 90% of males and 80% of females by the age of 21, impacted on the mental health of 14 to 16 year olds. It was

found that those with definite acne, particularly girls, had higher levels of emotional and behavioural difficulties, yet less than a third of participants had sought help from a doctor, with boys less likely to talk to friends and family about their acne.

Dr Anthony Bewley, a spokesperson for the British Skin Foundation and a psychodermatologist, is hopeful about what the survey can highlight to the public. He says: "It's important that we consider these results. Patients with skin disease often feel enormously upset about their skin condition, as it affects their confidence and self-esteem in so many different ways. All too often the impact of skin disease is underestimated, and this research makes it very clear that it is common for individuals with skin disease to consider suicide. Many patients consider their skin conditions to be more psychologically damaging than diabetes or heart disease."

Matthew Patey, chief executive of the British Skin Foundation, says: "The results make for depressing reading, but reflect the life-altering problems faced by many people living with a skin disease. Clearly there is an ongoing need for better awareness amongst the general population about what skin disease is and crucially, how severe conditions can get. We have to remember that, aside from the symptomatic effect any skin disease will have on the sufferer, it can also have a devastating effect on social relations, people around them and cause lasting damage to a person's mental health as well."

Summary of key findings from the survey:

Suicide and self-harm

- 17% of participants had contemplated suicide.
- Percentage of respondents who had attempted suicide: 1%.
- 16% of participants said they had self-harmed because of their disease.

Impact on social life and relationships

- 68% said a fall in self-confidence was the number one issue caused by their skin disease.
- 29% claimed their skin disease was an active barrier in finding a partner.
- 42% said the second biggest area affected was their work life.
- 56% said making new friends was the third biggest issue.
- 19% people with a skin disease had experienced a relationship breakdown.

Daily Life

- Participants who had been verbally abused by a member of public at least once: 46%.
- 12% had suffered physical abuse by another member of the public at least once.
- Participants who had been bullied regularly: 20%.
- 37% had received unfair treatment at work or full-time education.

Source: BSF press release

About BSF

The British Skin Foundation (BSF) is a charity committed to raising funds for skin disease research. 100% of the money raised for the charity goes back into funding vital research. Over the last four years, the BSF has awarded in excess of £2,700,000 to numerous studies, £1.8 million of which has been dedicated to research into the various types of skin cancer.

Warning about unlicensed arthritis treatment

Recently the Medicines and Healthcare products Regulatory Agency (MHRA) warned the public not to buy a potentially dangerous unlicensed and unproven medicine for arthritis and other medical conditions, which can be sold for as much as £168.00 for a 12-month's supply.

Arthroplex capsules and gel are being advertised illegally on the internet and through flyers in magazines claiming to relieve the symptoms of rheumatoid arthritis and joint pain. This product is unlicensed, meaning it has not undergone any testing for quality, safety and effectiveness so it could pose a serious health risk to people who use it.

The Advertising Standards Authority and the MHRA received more than 70 complaints about the advertising of the medicine that makes the claim to, ''Feel your aches and pains fade in 48 hours! And then disappear forever.''

David Carter, manager of the MHRA's medicines borderline section, said:

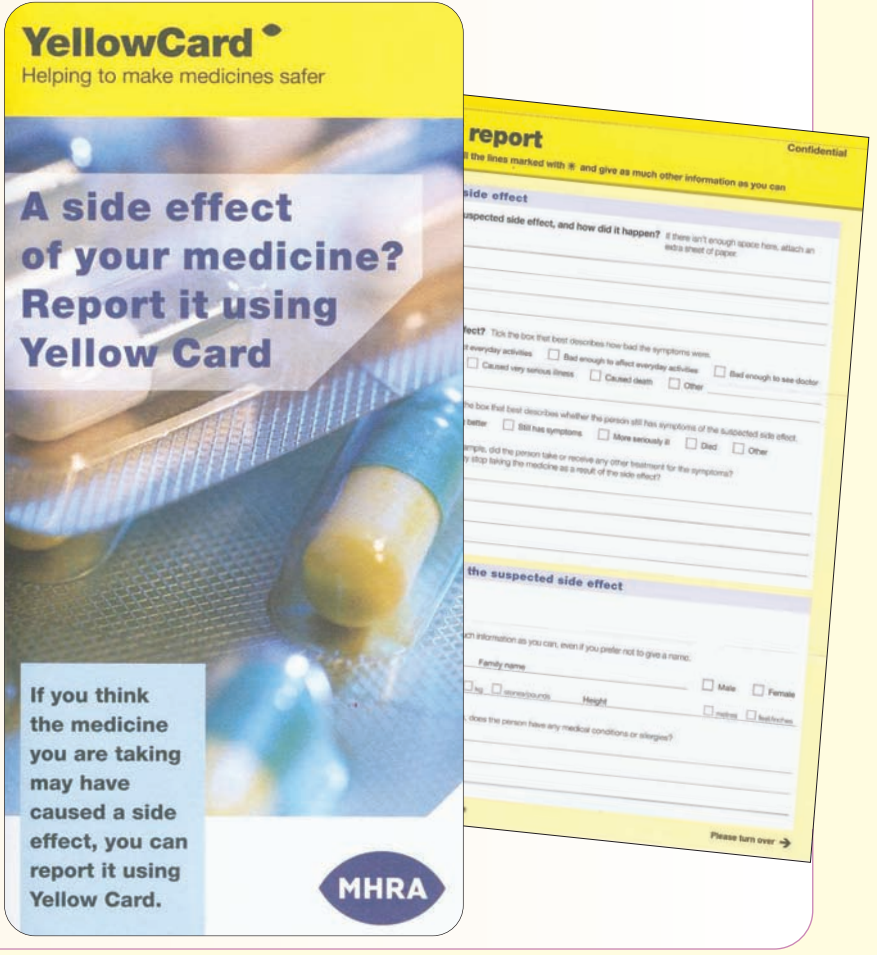
''Adverts like Arthroplex make attractive claims but the fact is just because products are described as natural it does not mean to say that they are safe. If you believe you are suffering from any of the medical conditions listed in the advertisements please seek proper medical advice.''

When buying a herbal medicine people are advised to look for products that display the Traditional Herbal Registration (THR) logo or a PL/THR number. These products have been assessed by the MHRA so that consumers can be confident that their quality can be assured and that they contain relevant information for consumers about how to use the product safely.

''If anyone has bought or used any of this product or have any concerns then please speak to your GP or healthcare professional.''

Professor Alan Silman, medical director of Arthritis Research UK, said:

''Supplements are widely used by people with arthritis as they seek to find effective pain relief or avoid taking potentially harmful drugs, and a small number can offer some relief. Often people prefer the sound of natural products. However, natural does not mean they are either safe – or effective. Some manufacturers often go to great lengths to play on people's hopes with outrageous claims, optimistic testimonials



and even pseudo-science to promise the impossible.

''People should be wary of unproven products bought online or from mail order, and need evidence-based, non-biased information which charities such as ours can provide, to help them make informed decisions.''

If you are worried about any issues related to this or other products you have purchased for your arthritis, you are advised to talk to your healthcare provider or GP.

You can anonymously report anyone selling or advertising Arthroplex to the MHRA on 020 3080 6000.

Have you used Arthroplex?

BBC 1 Fake Britain programme makers would like to speak to people who have bought the product and found it has not worked or those who have paid for it and it has not turned up. They are particularly keen to speak to people who suffer acutely and are annoyed about the apparently fraudulent claims made by the product. The new series of programmes is due to air in 2013.

If you have had this experience please email: emmawightwick@screenchanneltv.co.uk

SOURCE:
MHRA press release July 2012

About the MHRA:

The MHRA is the government agency responsible for ensuring that medicines and medical devices work, and are acceptably safe. No product is risk-free. Underpinning their work lie robust and fact-based judgements to ensure that the benefits to patients and the public justify the risks.

The MHRA keep watch over medicines and devices, and take any necessary action to protect the public promptly if there is a problem.

The agency encourages everyone – the public and healthcare professionals as well as the industry – to tell them about any problems with a medicine or medical device, so they can investigate and take any necessary action.

www.mhra.gov.uk

The Information Standard
Certified member
This organisation has been certified as a producer of reliable health and social care information.
www.theinformationstandard.org

Physiotherapy and exercise for psoriatic arthritis updated and fully revised

There is a large body of evidence for the benefit of exercise in inflammatory arthritis. This new revised and updated 16-page booklet will help you get started by giving some examples of good exercises for joints most commonly affected by psoriatic arthritis. It also answers some common questions about exercise and physiotherapy.

Written by a chartered physiotherapist with colour illustrations of the exercises, this leaflet will give you useful information before starting even the simplest of exercises.

Available free of charge from PAPAA.

Psychological aspects of psoriasis

Another new publication is a 20-page booklet on the psychological aspects of psoriasis has been produced and again is available free of charge from PAPAA.

The booklet considers the challenges of living with psoriasis and the negative impact it can have on an individual's life.

The information aims to describe the different ways that psoriasis may make you feel, think and behave. It offers some advice to help you manage the stress and low mood which is often associated with psoriasis.

Both booklets are available as downloads from our website.

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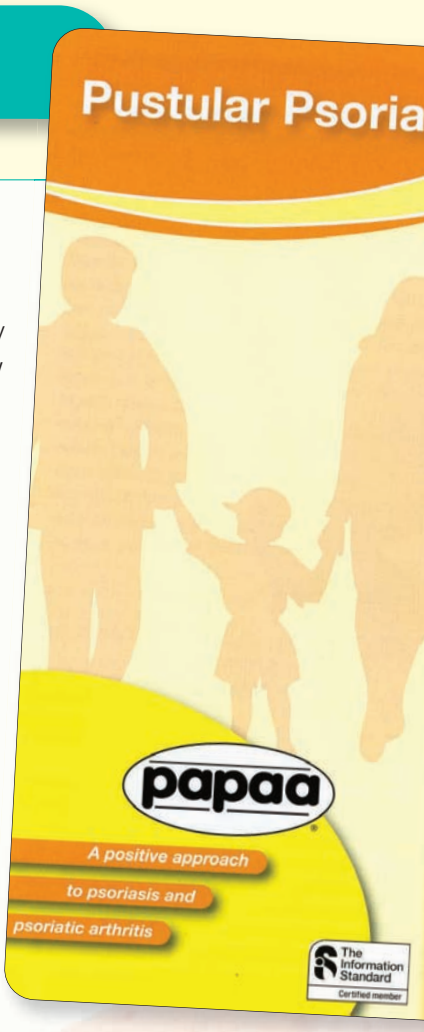


Pustular psoriasis

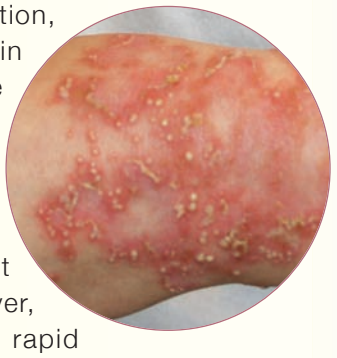
Pustular psoriasis tends not to look like plaque psoriasis, although plaque and pustular psoriasis can coexist or one may follow the other.

The main distinguishing feature of pustular psoriasis is the appearance of pus spots surrounded by red skin. This doesn't mean that there is any infection present. The spots simply show that the skin has been invaded by the same white blood cells that would be seen if there were to be an infection present.

It can be triggered by some internal medications, irritating topical agents, ultraviolet light overdoses, pregnancy, systemic steroids (especially sudden withdrawal of systemic or topical steroids), infections, perspiration or emotional stress.

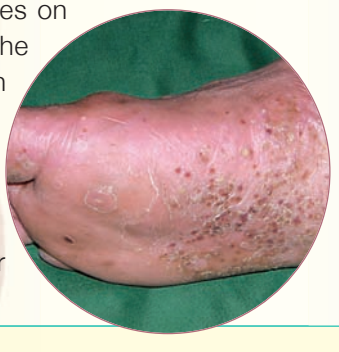
Generalised pustular psoriasis

Generalised pustular psoriasis is a rarer form of the condition, and especially rare in children. It can be abrupt, and triggered by an infection, pregnancy, low thyroid activity or any of a number of different drugs. It can cause fever, chills, severe itching, rapid pulse rate, exhaustion, anaemia, weight loss, muscle weakness and/or joint pain. Sometimes these attacks are followed by milder outbreaks of psoriasis. With this type, the pustules occur all over the body – patients can often become quite unwell and, as such, generalised pustular psoriasis often requires hospital in-patient treatment. **Please do note that this is a rare form of psoriasis.**



Palmer-plantar pustulosis (PPP)

Another form of pustular psoriasis, palmer-plantar pustulosis, causes pustules on the palms and soles of the feet. It tends to occur in people between the ages of 20 and 60, and is more common in people who smoke. Infection and stress are suspected trigger factors. PPP is normally recognisable by large yellow pustules up to 5cm in diameter in fleshy areas of hands and feet, such as the base of the thumb and the sides of the heels. They may be painful. The pustules then turn brown and drop off or peel. PPP is usually cyclical with new crops of pustules followed by periods of low activity. This form of psoriasis affects approximately 5% of people with psoriasis. It tends to go in cycles of:



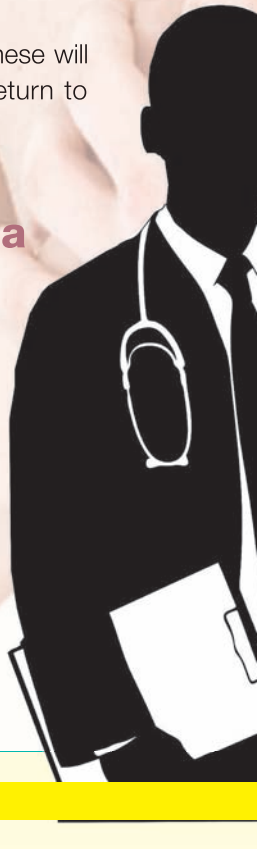
- **erythema (reddening of the skin) followed by:**
- **formation of pustules; and**
- **scaling of the skin.**

Topical therapies are usually a first-line treatment. PUVA and methotrexate are also sometimes used to clear the attack. However this type of psoriasis can be a little more difficult to manage.

In most episodes of pustular psoriasis these will last for a few weeks then disappear or return to erythrodermic psoriasis.

Acrodermatitis continua of Hallopeau

Another rare type of palmar-plantar pustular psoriasis, acrodermatitis continua of Hallopeau is characterised by skin lesions on the ends of the fingers and sometimes on the toes. The eruption occasionally starts after local trauma. Often the lesions are painful and disabling, with the nails often deformed, and bone changes may occur. This condition is quite hard to treat satisfactorily.



Treatment

Pustular psoriasis and PPP are usually treated with topical treatments. Sometimes topical steroids under thin dressings are prescribed. Pustular psoriasis can be stubborn to treat so sometimes other treatment regimes typically used for plaque psoriasis may be tried. Although not completely proven, for those who smoke, quitting appears to reduce the number of pustules as well as significantly reducing the erythema (redness) and desquamation (shedding of skin).

The main aims of the treatment of generalised pustular psoriasis are to restore the skin's barrier function, prevent further loss of fluid, stabilise the body's temperature and restore the skin's chemical balance. Imbalances, which can occur, might put added strain on the heart and kidneys, especially in older people. Because of possible complications with this form of psoriasis, if you're affected you should seek medical care immediately. The likelihood of hospitalisation for a short period of time depends on the severity of the outbreak. When hospitalised, bed rest, mild sedation, bland topical therapy, rehydration and avoiding excessive heat loss can improve the situation. It is important to remove as many of the potential trigger factors as possible. In some cases antibiotics are prescribed just in case an infection is also present. In severe cases, where the patient has become exhausted, other medications may be needed.

Methotrexate is the most common treatment for generalised pustular psoriasis. Ciclosporin is also used if your doctor needs to control the symptoms quickly. Oral steroids are often prescribed for those who do not respond to other forms of treatment or who have become very ill, but their use is very controversial. PUVA (the photsensitising drug psoralen plus UVA light) may also be used in the treatment of this condition after it has subsided.

Acrodermatitis continua of Hallopeau tends to be resistant to both topical and systemic treatments for psoriasis, so combinations of therapy may be tried. Most episodes of pustular psoriasis will last for a few weeks then disappear or remit to erythrodermic psoriasis.

Summary

- Pustular psoriasis is a rare form of psoriasis
- Severe cases need urgent referral
- Be aware of the trigger factors
- PPP is more common in people who smoke
- It tends to go in cycles
- Where pustules exist they may not necessarily be infectious
- Like psoriasis, the pustular version is not contagious.

Always consult your doctor or healthcare provider.

Our thanks to Dr Jennifer Crawley, fellow in medical dermatology, St John's Institute of Dermatology, London, who reviewed and revised the material.

The information is available as an 8-page booklet and as a download from our website.

To get a FREE copy:

Visit:	**www.psoriasis-shop.org**
Download:	**www.papaa.org**
Email:	**info@papaa.org**
Telephone:	**01923 672837**

Useful references

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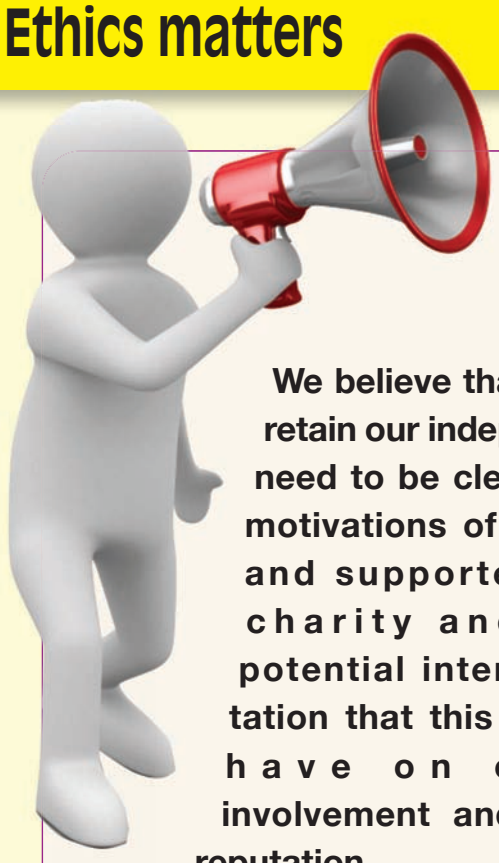
Ethics matters



We believe that in order to retain our independence we need to be clear about the motivations of the funders and supporters of the charity and the potential interpretation that this may have on our involvement and reputation.

PAPAA continually reviews its activities and consults with other organisations in order to provide services and activities that are appropriate for the changing needs of patients in the 21st century.

- The needs of people with psoriasis and psoriatic arthritis are and will continue to be the thrust of all activities the organisation delivers. These activities are delivered in an appropriate way that is based on good evidence and input from patients, carers and healthcare professionals.
- We provide information that has been approved by healthcare professionals or has been proven beneficial by published evidence.
- We provide a signposting service to help people with psoriasis and psoriatic arthritis to make an informed choice and understand how to deal with their condition in a constructive and confident way.

All PAPAA activities are funded via:

- **donations**
- **subscriptions**
- **charitable grants**
- **other income generation.**

Therefore as a charity, we rely on the various sources of income mentioned above to help us carry on our work of providing support, advice and free information to those affected by psoriasis and psoriatic arthritis.

The distribution of free information process is aided by healthcare professionals within the NHS who make our material available via outpatients areas and other clinical settings.

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.

Thank you

During the last few months, we continue to be very grateful to individuals who have chosen PAPAA as a charity to support through differing fundraising and awareness activities.

On 28th October Joanna Vaux took part in the BUPA Great South Run 2012.

Joanna said on her JustGiving page prior to the event: ''Please help me raise lots of money for PAPAA, which is a charity which continues to support those who suffer with psoriasis, a skin condition and psoriatic arthritis which can be the result of having the skin condition. This charity provides traditional patient support as well as new innovative approaches.

I have psoriasis and have done from an early age. When I was 17 I went into hospital with painful, large, swollen knees and toe joints to find I had psoriatic arthritis. At the time, I thought my chances of walking properly again were slim as I depended on a wheelchair. After prayer and ongoing medication. It wasn't long before I was able to walk independently and even run! 5 years later I want to support a charity which goes out of its way to support those like me, the literature they write is very supportive and helped me lots to understand what I had! There are lots of people who suffer very badly with psoriasis and psoriatic arthritis, who depend on the support from this charity and that's why I want to support them by running 10 miles at the Great South Run in October!''

Joanna surpassed her fundraising target and we wish to offer our congratulations and thanks for her efforts and support. ***Well done!***

If you would like to support PAPAA as your chosen charity, we are happy to provide you with material and support in order to make your activity or event successful.

We can also promote your event via our news feed on our website, via a JustGiving page, and post on Twitter and Facebook.
To find out what the latest fundraising activities are and how to get involved:

Visit: www.papaa.org/get-involved
Email: info@papaa.org
Telephone: 01923 672837

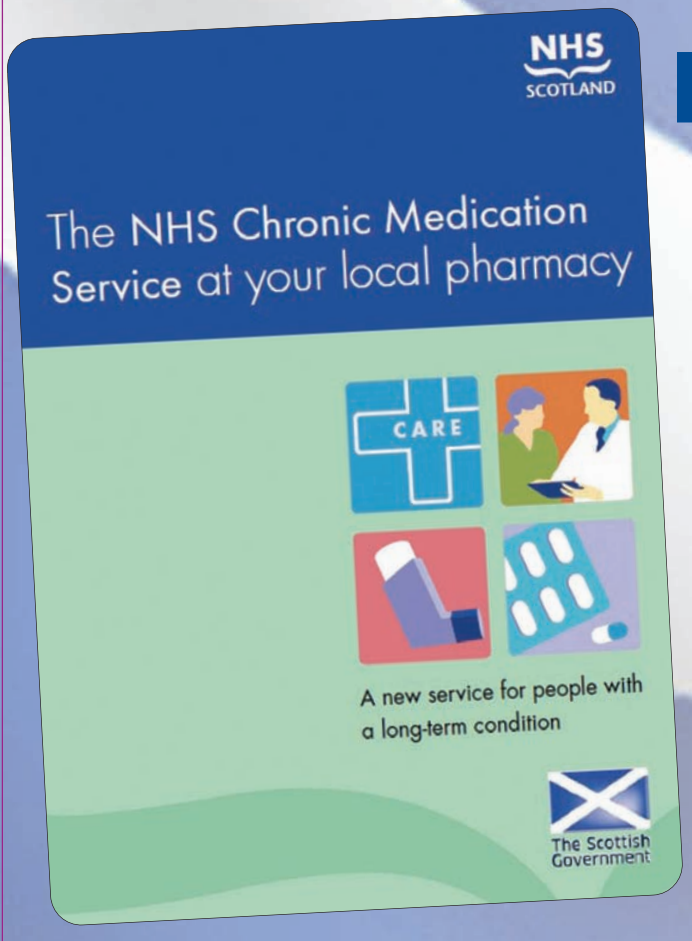
We will also be pleased to hear your ideas.

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



NHS Scotland

For people living in Scotland, the Chronic Medication Service (CMS) allows patients with long-term conditions to register with a community pharmacy of their choice for the provision of pharmaceutical care as part of a shared agreement between the patient, community pharmacist and general practitioner (GP).

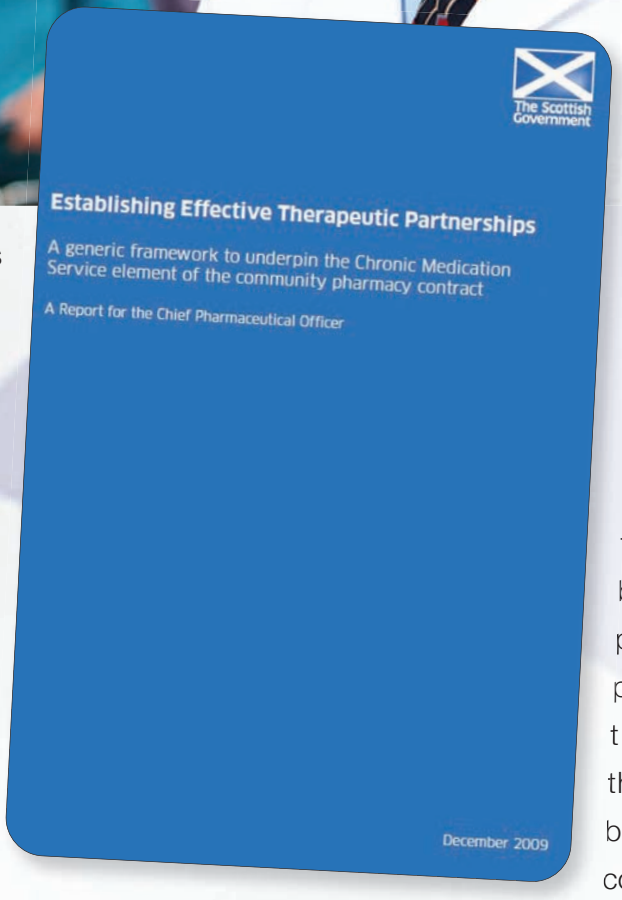
It introduces a more systematic way of working and formalises the role of community pharmacists in the management of individual patients with long-term conditions in order to assist in improving the patients' understanding of their medicines and optimising the clinical benefits from their therapy.

There are three stages to CMS:

Stage 1 involves the registration of patients for CMS. A patient with a long-term condition registers with a community pharmacy of their choice to receive CMS. He/she can only register with one pharmacy at any one time for the service. Registration is voluntary and includes an explicit informed patient consent process. This consent is given to the registering pharmacist.

Stage 2 introduces a generic pharmaceutical care planning framework which is based on the systematic approach to the practice of pharmaceutical care as described in the Clinical Resource and Audit Group (CRAG) framework document, Clinical Pharmacy Practice in Primary Care. Initially the pharmacist assesses registered patients to identify and prioritise individuals or patient groups with unmet pharmaceutical care needs in order to target patients most in need of their support. The pharmacist then undertakes to identify and record the patient's pharmaceutical care needs, care issues, any desired outcomes and the actions required to deliver those outcomes. These are documented in a pharmaceutical care plan.

Stage 3 establishes the shared care element which allows a patient's GP to produce a 24 or 48 week serial prescription for a patient, which is dispensed at appropriate time intervals determined by the GP. Information detailing the date of a dispensing event for a CMS serial prescription item is automatically sent back to the GP practice electronically after each serial dispensing episode. This stage is supported by CMS disease-specific protocols in order to determine any specific reporting or referral criteria for a number of pertinent disease conditions.



A GP can cancel any items on a serial prescription electronically. Once cancelled, the pharmacist can no longer dispense any quantities that remain outstanding for that item. If there is a change of medication or dosage, then the GP can generate a new serial prescription if appropriate. Once the last instalment from the serial prescription has been dispensed the pharmacist electronically sends an end of care treatment summary, which includes a serial prescription renewal request to the GP practice. The renewal request acts as trigger to request a new serial prescription for the patient. The end of care treatment summary details any relevant data such as compliance reporting and any recommended actions for the GP.

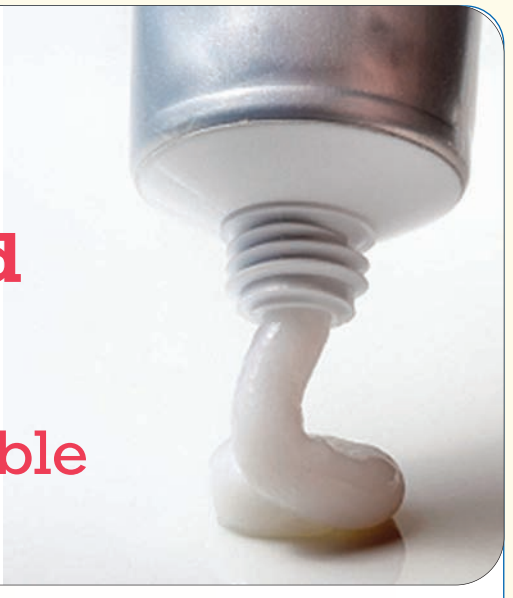
The Chronic Medication Service (CMS) is underpinned by a generic framework as outlined in the report Establishing Effective Therapeutic Partnerships. This report, produced by an advisory group under the chairmanship of Professor Lewis Ritchie, has provided a very solid foundation on which to build CMS, based on the principle of improving patient care through the establishment of therapeutic partnerships between patients, GPs and community pharmacists.

Further information is available along with download of the booklet from: www.communitypharmacy.scot.nhs.uk

The Establishing Effective Therapeutic Partnerships report is available from: www.scotland.gov.uk

Discontinued 60g tube

120g tubes available



The manufacturer of combination calcipotriol/betamethasone dipropionate (Dovobet®) ointment has announced a change to the pack size availability. From 1 November 2012, 60g tubes were discontinued, although 120g tubes will continue to be available for the near future.

The decision appears to have been made as part of the manufacturer's review of the psoriasis market in the UK, based on its own company survey of 150 people, 105 of whom said they preferred gel formulations instead of ointment. Interestingly, the gel will continue to be available in 60g tubes. So if you prefer the smaller 60g tubes of ointment then you might need to talk to your GP about how you manage your psoriasis in future.

As this product contains a steroid, it is worth remembering that the adult dose for the product indication for stable plaque psoriasis, according to the British National Formulary (BNF), is a maximum of 15g per day (100g per week) to be applied once daily to affected areas for 4 weeks.

The decision follows the manufacturer's previous changes last year to discontinue calcipotriol cream (Dovonex® Cream) and replace 120g tubes of calcipotriol ointment (Dovonex® ointment) in smaller 30g tubes. This product is a vitamin D analogue and does not contain a steroid combination.

About the BNF:

The BNF is a joint publication of the British Medical Association and the Royal Pharmaceutical Society. It is published biannually under the authority of a Joint Formulary Committee, which comprises representatives of the two professional bodies and of the UK health departments. The Dental Advisory Group oversees the preparation of advice on the drug management of dental and oral conditions; the group includes representatives of the British Dental Association. The Nurse Prescribers' Advisory Group advises on the content relevant to nurses.

The BNF aims to provide prescribers, pharmacists and other healthcare professionals with sound up-to-date information about the use of medicines.

www.bnf.org

Book Review

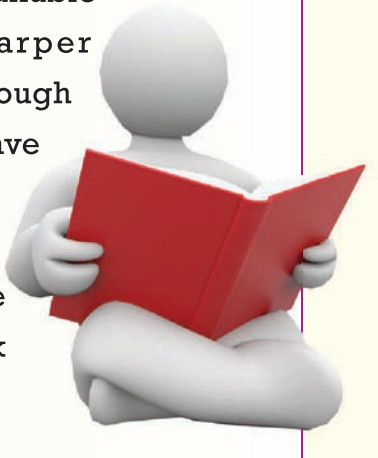
Bad Pharma is the latest publication by Dr Ben Goldacre. If you are not familiar with his work, Dr Goldarce is a best-selling author, broadcaster, medical doctor and academic who specialises in unpicking dodgy scientific claims from drug companies, newspapers, government reports, PR people and quacks. His view is that unpicking bad science is the best way to explain good science.

As a regular contributor to the Guardian newspaper Dr Goldacre is well known for his Bad Science column, which regularly picks away at spurious scientific and misleading claims.

In Bad Pharma, Dr Goldarce puts the global pharmaceutical industry under the microscope. What he reveals is a fascinating, terrifying mess. Doctors and patients need good scientific evidence to make informed decisions. But instead, companies run bad trials on their own drugs, which distort and exaggerate the benefits by design. When these trials produce unflattering results, the data is simply buried. All of this is perfectly legal. In fact, even government regulators withhold vitally important data from the people who need it most, according to Dr Goldacre.

Doctors and some patient groups have stood by too, and failed to protect patients. Instead, they often take money and favours, in a world so fractured that medics and nurses are now educated by the drugs industry.

The paperback (ISBN: 978-0-00-735074-2) edition is available from Fourth Estate (Harper Press) at £13.99, although online book sellers have copies available at £9.79 (delivered) for the print version and £8.99 for the download electronic book e-reader version.



www.badscience.net

Letters

Q Dear PAPAA,

I am having trouble getting Polytar Plus shampoo and recently my pharmacist said it is no longer available. Can you recommend an alternative?

Yours CT

A Dear CT,

We are unable to recommend any particular product and your doctor will be able to provide such advice. Although, we have made enquiries regarding the difficulty you are having obtaining Polytar Plus shampoo. The product owners confirmed that due to a manufacturer closing down, the Polytar range would not be available until at least April or May 2013. You may like to know that there are a number of products available which contain tar. You should seek advice from your healthcare provider as to the most appropriate product for your circumstances.

Yours PAPAA

Q Dear PAPAA,

I read your report with great interest on the NICE recommendation that people with psoriasis should be checked annually for psoriatic arthritis.

I was referred by my GP in March 2010 to a dermatologist and was diagnosed with psoriasis.

I had several bouts of iritis and uveitis prior to this and was always told at the eye clinic that "there must be some form of inflammation in your body", but unfortunately no blood tests or referrals were made. I feel let down by both the eye clinic and dermatologists because all the time I was saying my joints hurt.

I had a fall in August 2011 which led me to be referred to a consultant who diagnosed spurs bursitis and frayed rotator cuff. Thankfully, he then thought that my psoriasis and joint pain warranted a referral to a rheumatologist, who suspected psoriatic arthritis as I also had pitted nails. An untrasound and bloods confirmed his suspicion.

Prior to this I felt no one was really interested in me and I knew something else was wrong (I was beginning to think it must all be in my head!). If I had been checked out as the report recommends, I would have been on the treatment earlier.

Yours DM

A Dear DM,

Thank you for your comments submitted via our website.

You make some valid points, and getting psoriatic arthritis recognised early is key to long-term management. Although, often the collection of apparently unconnected symptoms can make immediate diagnosis difficult, it is sometimes an event as you describe that pulls the symptoms together. ***Yours PAPAA***

Editor's note: Uveitis can be associated with psoriatic arthritis, so if you are having problems with your eyes make sure you ask your doctor for advice. We also produce a fact sheet called psoriatic arthritis and the eyes, which is available on our website or as a hard copy.

Q Dear PAPAA,

I would like to say thank you for all the information that you sent to me. It was very useful.

I am now in my forties and have suffered with psoriasis since the age of 12. I have also suffered with a very stiff and painful neck for a number of years. After various visits to my GP I was told it was rheumatism, given pain killers and sent away.

However, earlier this year, after suffering from a chronic back strain injury I was made redundant from my employment. One month later my index fingers started to swell and then both of my knees followed suit. I was in a great deal of pain and was taken to my GP. I hobbled into the surgery (I resembled the tin man from the Wizard of Oz) I was told I could have rheumatoid arthritis and sent for blood tests. I went home to rest and took the tablets I had been prescribed. Whilst at home I picked up a magazine and started to read various letters. One which took my eye was from a lady who had heard that arthritis and psoriasis were linked. I was amazed, for I was quite ignorant of this condition.

I returned to my GP to be told that there was no rheumatoid factor in my blood. I then mentioned psoriatic arthritis to my GP and she confirmed the link. I was eventually sent to see a rheumatologist and my own diagnosis was confirmed. Six months on I have been given a DMARD and NSAID but I find it hard to tolerate these drugs. I am now still in a great deal of pain and I have to use a wheelchair for shopping and other outings.

I was also told by my rheumatologist that my stiff neck was perhaps the onset of psoriatic arthritis, but had been overlooked. I know that this form of arthritis is difficult to recognise but perhaps GPs should be made more aware of this painful and disabling arthritis. Perhaps the good work that PAPAA is doing will achieve this.

Yours PC

A Dear PC,

Thank you for your email. You highlight a continuing theme that we hear from the many people that contact us. It is clear that psoriatic arthritis is often overlooked or not considered when people present with psoriasis. Hopefully the more we can raise awareness, the more likely the condition will be picked up earlier.

Yours PAPAA

Editor's note: As the writer above mentioned it is often items in magazines or posters in waiting rooms that alert people to the possibility of having these conditions. If you see or you know of potential opportunities to raise awareness about psoriasis and psoriatic arthritis, please let us know as we are always happy to supply posters, leaflets and other display material.

Please note: letters and emails have been edited and names withheld for privacy

Writings on the wall

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

Hello PAPAA

I've just found your site via NHS Choices site, and it is very informative and helpful – I have ordered the free info pack initially and then I will take my time to read and learn more about psoriasis. Having only just been diagnosed with psoriasis, it was very daunting, but I have found your site more helpful than many of the doctors I've seen, therefore I send you thanks for an excellent site. I would also like to say your related hyperlinks are invaluable!

Best wishes HF

"...I was diagnosed with psoriasis/psoriatic arthritis in 2004 and have tried a few different creams and lotions but it still keeps coming back now I am in the middle of another spell of treatment on PUVA light the one with the tablets taken 2 hours before now this helps me tremendously as it more or less clears completely for a considerable time around 2 years until something makes it flare up again which I think is the arthritis especially in damp or winter conditions and its back to square one I'm afraid so back to hospital again for another 24 sessions on the light again..."

"...I have just this week been diagnosed with psoriatic arthritis although looking back I have symptoms for the last 2 years, I have had psoriasis since I was 13, I am now 36. I have spent the last few days researching as much as I can, it's still sinking in that I have got PsA. It's good to see that there are places I can turn to for information and support...
... Just diagnosed with PsA. Awaiting appointment from specialist. Currently struggling a bit with the tiredness..."

"...I am about to turn 28 and I was diagnosed when I was 20 with psoriatic arthritis. I have had psoriasis since I was 8. I am spiraling out of control. Takes me at least 40 mins just to get out of bed in the mornings. Can't walk correctly anymore. I have severe swelling my my spine, neck, collar bone, elbows, fingers, pelvic bone, and knees. Does anyone have any suggestions of things that I can do to ease the pain? NSAIDs no longer help me..."

"...I was diagnosed with psoriasis when I was 15 years old, I am now 21. I have been on numerous medications over the years and most recently was a biologic subcutaneous injection I gave myself once a week. I am now 5 months pregnant and I can no longer take any medication for it. My skin has gone crazy, getting new spots daily. My head is like one big red flaky patch and now I have 2 on my face. Has anyone else had to deal with this while pregnant? How did you manage to not rip your skin off? ..."

SOCIAL MEDIA

Follow us on Facebook

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

Log onto 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, disability claims amongst other topics.

We post interesting news items and links to fuller articles on our website.

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.

Marketplace

Here are some items brought to our attention by our readers.

The first is not a new product but can be extremely useful if you have arthritis. Threading a needle can be a tricky job. Using self-threading needles may help make the job easier.

The example in the image above is from Betterware and priced a £2.99, although you can also find similar products from a Haberdashery shop or department stores.

Do you have trouble getting your socks on?

There are a range of devices that can aid in the process. **Sock Assist** is just one such product. It lays flat on the floor, accommodates feet and calves of all sizes, has a non-stick surface and pulls the sock up the calf instead of releasing it at the ankle. Its innovative design allows easy donning of socks or knee-high nylons using one or two hands.

Also works with elastic compression knee high socks or stockings.

Available from the Disability Warehouse at a starting price of about £20.00

Other similar products are available with prices starting at £3.65 for the Sock Aid below.

If you are interested in these types of products a good tip is to use a price comparison website and enter search terms such as 'easy thread needle' or 'sock puller' and you will get few results to compare price and suitability.

Nylon pancake/omelette turner

If you are having trouble with your wrists or find lifting food from a pan difficult, how about this product that a reader has suggested to us. A pancake/omelette turner, made from nylon, although it could possibly be used for numerous other applications.

The product in the picture is priced at £3.49 from various outlets, but if you search online, there are similar products available, although prices do vary considerably.

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.

Getting the best prices online:

Price comparison sites - enter the search phrase 'compare prices' into a search engine and then access the sites directly.

Remember to check availability of products, cost of delivery and most of all whether the site is secured for ecommerce transactions.

- **www.dealtime.co.uk**
- **www.comparestoreprices.co.uk**
- **www.kelkoo.co.uk**
- **www.google.co.uk/products**

Secure sites will have a certificate on the site, such as **GoDaddy, DigiCert, VeriSign, Thawte** and **Comodo**. These certificates will allow you to check site validity, if you are suspicious.

Contact details for the featured products:

www.betterware.co.uk
0121 693 2667

www.disability-warehouse.co.uk
0191 516 6848

*Please note prices are only for guide purposes and you may find products vary, so it's worth searching online for best prices and delivery charges.

If you come across products or items that you have found useful or you think others will find of interest please let us know. There may be similar products on the market made by other manufacturers that are as useful so keep your eyes open.