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Dear Reader

Once you have been diagnosed with a condition, the next question is probably "how can I get rid of it?" Unfortunately for conditions like psoriasis and psoriatic arthritis there aren't any cures, but with good management they can be controlled. In this issue we've looked at the current available treatments for psoriasis (pages 4-6) and when to treat psoriatic arthritis (pages 10-12).

As part of the process of deciding on what is the appropriate course of therapy, doctors take into account a number of considerations. The National Institute for Health and Clinical Excellence (NICE) has just published draft psoriasis guideline to help healthcare professionals in this process (page 3).

Often, treatments don't work or have unwanted side effects, so further research or monitoring is required. The Medicines and Healthcare Regulatory Agency (MHRA) is responsible for collecting reports of side effects via the yellow card scheme (page 13), to which members of the public can also contribute.

Finally, the search for a cure continues and the discovery of a gene involved in psoriasis (pages 14-15) is an interesting development that may prove to be invaluable for future treatment pathways.

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:

Finding the right treatment for psoriasis and psoriatic arthritis is often the proverbial search for a needle in a haystack, it's there, but not always obvious.

You may have noticed the black and white box of random dots on the bottom left of the cover. It's a QR (quick response) code which is for smartphone scanners. Download a reader app and scan the code with the camera on your phone and it will take you straight to the PAPAA website home page.

NICE seeks views on draft psoriasis guideline

People with psoriasis should be treated by their GPs whenever possible and only referred to dermatology specialists when there is a clinical need, suggests draft guidance published in May from the National Institute for Health and Clinical Excellence (NICE).

In its draft guideline, NICE proposes to advise that GPs and other non-specialist healthcare professionals should only refer patients to dermatology specialists if they are uncertain about the diagnosis, the psoriasis is severe or extensive, the condition can't be controlled with topical therapies (such as ointments and creams), or if the psoriasis is affecting the person's physical, psychological or social wellbeing. Patients should also be referred if they have a type of the condition called acute guttate psoriasis which requires phototherapy, or if the psoriasis is causing distinctive nail changes that are having major impacts cosmetically or on day-to-day activities.

Dr Phil Alderson, medical associate director of the centre for clinical practice at NICE said: "Psoriasis can have profound functional, psychological and social effects on a person's life and so it is important that people have access to effective treatments in a timely manner and according to the severity of their condition. Currently there are wide variations in clinical practice in the management of the condition, particularly regarding access to specialist treatments, appropriate drug monitoring, specialist nurse support and psychological services. Greater responsibility for the condition within primary care could improve access to treatments and support for people with this highly visible and potentially stigmatising disease."

Another recommendation proposed by NICE in its draft document is to assess everyone with psoriasis for psoriatic arthritis every year. This is especially important during the first 10 years of having psoriasis. Up to 30% of people with the condition develop psoriatic arthritis, which causes pain, stiffness and swelling in and around the joints.

Also, NICE suggests that doctors should explain to their patients with psoriasis that they will be at a greater risk of hypertension, diabetes, obesity and hyperlipidaemia than people without the condition, and so they should be offered preventative advice and healthy lifestyle information, in line with previously published NICE guidance.

Psoriasis is a skin condition characterised by red, flaky, crusty patches of skin covered with silvery scales. It is believed to affect up to 2.2% of the UK population (over 1.3 million people). The effects of psoriasis vary greatly from person to person; for some it can be a minor irritation, but for others it can have major effects on their functional, psychological and social wellbeing.

While there is no cure for psoriasis, treatments are effective and can include topical therapies, phototherapy (eg controlled exposure to ultraviolet light) or systemic therapies (eg oral and injected medicines), depending on the severity of the disease.

Dr Alderson added: "We have published these draft recommendations as part of a public consultation and so encourage our stakeholders to send us feedback during this period. Once published, we hope that our clinical guideline will provide clear advice for the NHS on the management of all types of psoriasis in order to improve comfort and minimise the effects of living with this condition."

The deadline for submitting comments on the draft guideline is 5pm on Tuesday 10 July 2012. NICE expects to publish final guidance for the NHS in October.

SOURCE:

NICE press release May 2012
www.nice.org.uk

Treating psoriasis

Although there are no cures for psoriasis, it can be controlled and go into remission (go away). Not all people will be affected in the same way and doctors will class the condition as mild, moderate or severe. The following are the range of treatments used in the UK for treating psoriasis. The treatments are listed alphabetically and not in the order of use, and is for reference only.

Antifungals

The use of antifungal agents in psoriasis care tends to revolve around the treatment of seborrhoeic dermatitis and scalp psoriasis.

They are useful in removing fungus which has been linked to conditions such as dandruff and scaly scalp conditions. Some commonly used antidandruff shampoos claim to have activity against fungus microbes.

Prescribed antifungals can be used alone or in combination with topical corticosteroids, and antibacterials or both. They are sometimes incorporated into a treatment regime to prevent fungal infection on skin which could be prone to it.

Coal tar

Coal tar therapy has been used for more than a century in dermatology. It is a topical (applied to the skin) treatment mostly used for acute scalp psoriasis. It has anti-inflammatory properties that are useful in chronic plaque psoriasis; it also has anti-scaling properties. Crude coal tar (coal tar BP) is the most effective form, typically in a concentration of 1 to 10% in a soft paraffin base, although few people with psoriasis tolerate the smell and mess.

Cleaner extracts of coal tar included in proprietary preparations are more practicable for home use but they are less effective and improvement takes longer.

Contact of coal tar products with normal skin is not usually harmful and they can be used for widespread small lesions; however, irritation, contact allergy, and sterile folliculitis can occur. The milder tar extracts can be used on the face and flexures. Tar baths and tar shampoos are also helpful.

Coal tar has also been used in combination with ultraviolet B light in hospitals, a treatment known as the Goeckerman method.

Combination therapies

Sometimes clinicians will prescribe a product containing one or more active ingredients with different functions. This may be in order to simplify the number of treatments being applied at any one time or because the agents combined together have been shown to act better than when used independently. There are a large number of combinations.

Dithranol

Dithranol has been used for more than 100 years in the treatment of psoriasis. It is a chemical of plant origin, taken from the bark of a South American tree. Dithranol in Lassar's paste is used most successfully for inpatients in the hospital environment. However the use of dithranol is not without drawbacks. Dithranol permanently stains both skin and clothing and can burn non-affected skin.

While this can be controlled by careful application in hospital its compliance is poor when used as outpatient therapy. There are also a large number of concentrations for doctors to use and the tendency has been for people to be prescribed different concentrations to be used in either a ‘step up’ or ‘step down’ fashion.

Proprietary dithranol-containing products are more acceptable. They can be used in ‘short contact regimes’, being applied to the psoriatic plaques and left for up to one hour before washing off. This method reduces dithranol burning and staining.

Emollients

Emollients soothe, smooth and hydrate the skin and are indicated for all dry or scaling disorders. Their effects are short-lived and they should be applied frequently even after improvement occurs. They are useful in dry and eczematous disorders, and to a lesser extent in psoriasis. Light emollients such as aqueous cream are suitable for

many patients with dry skin but a wide range of more greasy preparations, including white soft paraffin, emulsifying ointment, and liquid and white soft paraffin ointment are available; the severity of the condition, patient preference and site of application will often guide the choice of emollient. Emollients should be applied in the direction of hair growth. Some ingredients may rarely cause sensitisation and this should be suspected if an eczematous reaction occurs. If you experience any discomfort whilst using emollients talk to your doctor about this as he may be able advise on more suitable products

Preparations such as aqueous cream and emulsifying ointment can be used as soap substitutes for hand washing and in the bath; the preparation is rubbed on the skin before rinsing off completely. The addition of a bath oil product may also be helpful.

Preparations containing an antibacterial should be avoided unless infection is present or is a frequent complication.

Urea is employed as a hydrating agent. It is used in scaling conditions and may be useful in elderly patients. It is occasionally used with other topical agents such as corticosteroids to enhance penetration.

Immunosuppressant and biologic agents

Methotrexate was discovered to be effective in clearing psoriasis in the 1950s and was eventually approved for this use in the 1970s. In psoriasis, methotrexate works by preventing the excessive division and multiplication of skin cells that causes the skin scaling and raised plaques in this condition. It is used when the condition is severe and unresponsive to conventional treatments as it has many potential side effects.

Ciclosporin is another immunosuppressant, originally used to prevent transplant patients from rejecting their new organs. Doctors noticed that transplant patients who had a previous history of psoriasis tended to have fewer plaques post-transplant and research suggested that it was the ciclosporin that was having this effect.

Biologic agents are relatively new entrants into the field of psoriasis management and are made from biological (human or animal-based) proteins rather than artificial chemicals, much in the way that insulin was made from animal sources in the past. Biologic agents are different from other medications for psoriasis as they are designed

to block the condition in the immune system rather than waiting to treat the symptoms of the disease.

Phototherapy

People with psoriasis can sometimes be referred to a specialist hospital unit for ultraviolet light therapy. UVB light is used to help trigger chemical reactions that affect the function of the cells by reducing their ability to reproduce so quickly.

UVB is used to treat guttate psoriasis or plaque psoriasis which fails to respond to simple topical treatments.

There are two types of UVB treatments: broadband and narrowband. Narrowband UVB (TL01) is the commonest type of UVB treatment in the UK. Narrowband UVB works in much the same way as broadband UVB.

PUVA (psoralen and ultraviolet light A) is another form of UV light treatment using ultraviolet A light and a plant extract called psoralen. This chemical makes the skin more sensitive to light and increases the effect of the UVA light. Psoralen is derived from plants and is normally taken as a tablet or by bathing in a psoralen solution. Like UVB treatment this is usually administered in hospital.

Retinoids

Retinoids are a derivative of vitamin A and can be used both orally and by direct application to the skin. They should not be confused with the vitamin A products that are bought from chemists or supermarkets as vitamin supplements.

Oral acitretin is an effective vitamin A-based treatment for psoriasis. It is only prescribed by dermatologists in a hospital setting for severe, extensive, refractory psoriasis (non-responsive). It has a long half-life, which means it remains in the body for a considerable period of time after

treatment and its persistence in tissues requires that contraceptive measures must be used by women during and for at least two years following therapy as it can harm the development of unborn children.

By contrast, the topical retinoid is used for the treatment of mild to moderate plaque psoriasis.

Steroids

Topical corticosteroids are used for the treatment of inflammatory conditions of the skin (other than those arising from an infection). They are effective in conditions such as eczema and psoriasis.

Corticosteroids only suppress the inflammatory reaction during use; they will not cure the condition and the skin problem may get worse once the use of topical corticosteroids stops. This is called a rebound effect. They are generally used to relieve symptoms and suppress signs of the disorder when other measures such as emollients are ineffective.

Over the years a number of topical topical corticosteroids have been developed of different strengths. They are now categorised into four strength categories: mild, moderate, potent and super potent.

Different strengths are used by doctors depending upon the patient and the size and severity of the condition.

The risk of side effects runs parallel with the strength of the steroid, the duration of therapy and, to some extent, how much the skin is exposed to the air. The face, genitals and skin fold areas will absorb more steroids than other areas. If you use a steroid under a bandage it will also have the same effect. Side effects on the skin may be apparent within two weeks' use. The potent and super potent steroids should be carefully monitored and limited to a few weeks' use, after which a milder steroid should be substituted if possible. Patients should be reviewed every three months. Only mildly and moderately potent steroids should be used in children to avoid potential growth side effects and long-lasting cosmetic disfiguration.

Vitamin D analogues

Vitamin D analogues, calcipotriol, calcitriol and tacalcitol, should not be confused with vitamin tablets or liquids that you may take as dietary supplements. While their chemical structure may be based on a vitamin D3 molecule they have been modified to have a completely different effect.

They slow down the overproduction of skin cells and stimulate the skin, correcting the abnormally fast cell turnover that characterises psoriasis. Unlike naturally occurring vitamin D, they have less effect on calcium metabolism, so the risks of high levels of calcium in the blood (hypercalcaemia) or in the urine (hypercalciuria) are reduced. Nevertheless there are limits to how much can be used at any one time to limit the possibility of these side effects happening.

More recently one of these agents has been combined with a topical corticosteroid to help reduce skin inflammation as well.

Not all treatments available are suitable in every case of psoriasis. Your doctor will discuss with you the reasons why a certain treatment has been prescribed, and this should include the risks and benefits of that treatment.

Always follow your healthcare provider's advice

and discuss any side effects you experience as this will help to decide the most appropriate course of therapy.

New improved website

At the beginning of March this year we launched our new improved website. The site has been developed with input from people affected by psoriasis and psoriatic arthritis and designed to take visitors through the information in logical steps.

We have all aspects of psoriasis and psoriatic arthritis covered on the site, from basic information to more in-depth material, including treatments, education and self-help programmes. You will also find links within the site to signpost you to other sources of information.

Since the launch, the new site has seen a steady increase in traffic and referrals from other websites. The most popular searches are for treatments and self-help, which we've now highlighted on the home page.

The use of mobile technology is increasing and it is interesting to see that more than 30% of visits to the site are via mobile devices, with Apple iPhone and iPad dominating the list, but other devices, such as the Samsung Galaxy and HTC smartphones are high on the list of the 170 models of mobile devices that have been used.

If you feel there is any information missing or needs to be added to our information content please let us know as we continue to strive to provide comprehensive information.

Why not visit us at:
www.papaa.org

The Information Standard

Last year PAPAA was certified as a provider of high quality health and social care information by The Information Standard scheme.

As part of the scheme member organisations have an annual check by an external evaluator; our first took place in March and following the visit we are delighted to continue to be a member of the scheme.

It was particularly pleasing to be praised for the many compliant aspects of our processes; our use of lay reviewers was classed as beyond what most organisations had been undertaking and as 'good practice' in the final report. This is due to the enthusiasm of our valued volunteer lay reviewers, whom we must thank, as without **you** we wouldn't have achieved such a good report.

We are extremely grateful to everyone who has recently answered our call for help and we'll be sending out material for you to review very soon.

Anyone interested in becoming part of our lay reviewer team, please let us know and we'll send you full details of how to take part.

About the Information Standard

The Information Standard is a certification scheme for health and social care information. It is an independent scheme supported by the Department of Health. Any organisation that produces health and social care information can apply to join the scheme. If an organisation successfully meets the quality criteria of the standard and becomes certified, it can place the quality mark on its materials.

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

The quality mark is a quick and easy way for the public to identify reliable and trustworthy sources of information. The scheme's certified members are a mix of national charities, NHS organisations, voluntary, statutory and commercial organisations. The scheme is growing as organisations are in the process of gaining certification. For more information **www.theinformationstandard.org**

Improving patient choice

Patients in parts of London, Manchester, Salford and Nottingham will shortly be able to register with a GP practice of their choice for the first time. The PCTs involved in the pilots are Westminster, City & Hackney, Tower Hamlets, Manchester, Salford and Nottingham City. GP practices in these PCT areas will be able to join the pilot on a voluntary basis.

Under government plans to allow patients to choose the GP surgery that best suits their needs, from April they will be free to register with any practice in their city, for example, near their workplace or home.

It means people in these major cities, like commuters who are often away from their local area during the working day, will find it easier to see their doctor where it suits them. Participation will be voluntary.

The pilot scheme will run for one year, and will also benefit people who are moving home and wish to remain with their preferred practice, and families who would like a practice near to their children's school.

Health secretary Andrew Lansley said:

"I know from speaking to patients that they are frustrated that they are only allowed to go to the GP nearest their home rather than the one that best suits their needs.

"So I am delighted that... patients in London, Manchester and Salford and Nottingham will be able to start seeing their GP at a time and place that suits them.

"This is part of a range of measures we are introducing to shift the NHS to put patients' interests and desires at the heart of services."

Chair of Central London CCG Ruth O'Hare said: "We have a lot of people coming into London to work who need to take time off if they need to see a GP. A much simpler solution would be to allow them to register with a GP practice who has signed up to deliver this service, close to their work, where they could pop out for an hour and then go back to work."

SOURCE:
Department of Health

Psoriasis research

More expensive biologic treatments for psoriasis were only marginally more effective than standard treatments, according to a new study led by researchers in the Perelman School of Medicine at the University of Pennsylvania. Researchers found that previously reported response rates from randomised controlled trials were higher than results in a clinical, real-world setting. The research was published in the Archives of Dermatology, one of the JAMA/Archives Journals.

The researchers found that biologics were slightly more effective than a standard drug treatment for psoriasis, methotrexate, but that their impact was less then what has been reported in clinical trials which study efficacy of a medication under idealised circumstances and only for a short period of treatment.

"When one looks at the outcome as being clear, or almost clear [skin], the biologics appear to be more effective than methotrexate," said study author Joel Gelfand, MD, assistant professor of dermatology and epidemiology. But, when total body surface area affected by the disease is added in that difference diminishes, he said. More importantly, patients noted no differences in health-related quality of life with the newer biologic medications compared to methotrexate which has been used for psoriasis for over 40 years.

Gelfand noted that while the newer biologics are generally tolerated better by patients, with fewer side effects that lead to stopping the medication, their effectiveness diminishes with time. Traditional treatments may cause nausea and other potential side effects. Since psoriasis is a lifelong disease, patients on biologics are often left with only a relatively short period of optimum control of their psoriasis.

Biologics can cost £10,000 a year, compared to a couple of thousand pounds for older drugs or phototherapy, said Gelfand.

SOURCE:
Perelman School of Medicine
Press release

Good news on safety for biologics

A study on The British Association of Dermatologists' Biologic Interventions Register (BADBIR), a web-based register of biologic and conventional systemic therapies for psoriasis, has been published in the British Journal of Dermatology.

Biologic therapies for psoriasis have been licensed for at least six years in the UK and there are currently four available. Biologics work by blocking key inflammatory immune responses important to the development of psoriasis. They are administered either by subcutaneous or intravenous injection at intervals ranging from twice weekly to four times per year. As with most drugs, there are risks and side effects. Because this type of drug is new these risks and side effects need to be monitored carefully. The primary function of the BADBIR is to monitor the long-term side effects to ensure patient safety.

The register is in its fourth year and will run until at least July 2018. It currently involves over 3,000 patients, with around two thirds receiving biologic therapies and another third (the control group) receiving conventional systemic therapies such as methotrexate. The BADBIR has created a robust, high-quality, web-based register of biologic and conventional therapy for psoriasis in the UK and Ireland.

It is the largest project undertaken by the BAD, currently 130 dermatology departments are involved. The data it will provide over the coming years will be invaluable for the safe use of biologics in clinical practice. A UK and Ireland-wide dermatology clinical research network has been established that provides a framework for future studies in other diseases. The patient database also provides a useful resource for further research into psoriasis and some new studies have already begun as a result of this.

Professor Chris Griffiths (University of Manchester), chief investigator on the project, says:

"The BADBIR is a powerful, internationally-leading resource for study of the long-term, real-life risks and benefits of systemic therapies used for psoriasis. The information it will provide over the coming years will enable dermatologists to deliver the highest quality care for patients with psoriasis. It is particularly exciting to observe the enthusiasm with which dermatologists and their teams throughout Britain and Ireland have embraced the opportunity to participate in the BADBIR."

Since the BAD is running the registry, any bias should be avoided and so the results obtained from it must be recognised and acknowledged. "Patients should be entitled to receive the most appropriate treatment for their psoriasis, and this registry will help to highlight both the positives and negatives in order for them to make an informed choice regarding their treatments."

Psoriatic arthritis - when to treat

Who is involved in treating psoriatic arthritis?

After receiving a diagnosis of psoriatic arthritis the next step is to decide what sort of treatment would be best for you. This process will involve discussion with a team of healthcare professionals involved in your care. This team is usually, but not always, led by your doctor (GP) and may include:

- a rheumatologist
- a dermatologist
- a physiotherapist
- a specialist nurse
- an occupational therapist
- a podiatrist.

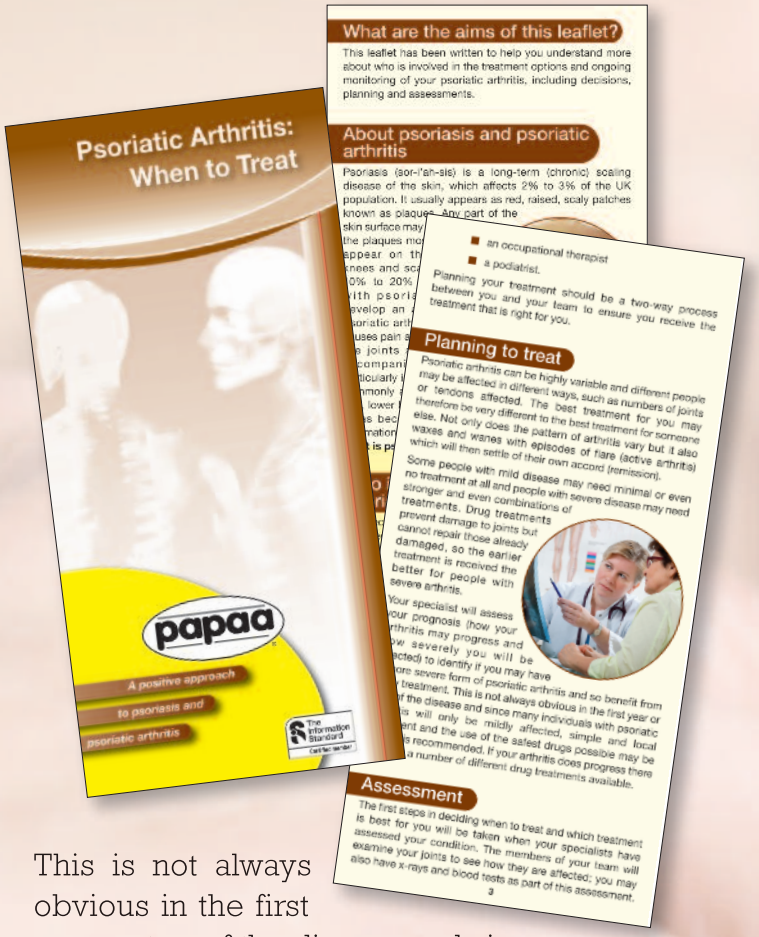
Planning your treatment should be a two-way process between you and your team to ensure you receive the treatment that is right for you.

Planning to treat

Psoriatic arthritis can be highly variable and different people may be affected in different ways, such as numbers of joints or tendons affected. The best treatment for you may therefore be very different to the best treatment for someone else. Not only does the pattern of arthritis vary but it also waxes and wanes with episodes of flare (active arthritis) which will then settle of their own accord (remission).

Some people with mild disease may need minimal or even no treatment at all and people with severe disease may need stronger and even combinations of treatments. Drug treatments try to prevent damage to joints but cannot repair those already damaged, so the earlier treatment is received the better for people with severe arthritis.

Your specialist will assess your prognosis (how your arthritis may progress and how severely you will be affected) to identify if you may have a more severe form of psoriatic arthritis and so benefit from early treatment[2].



This is not always obvious in the first year or two of the disease and since many individuals with psoriatic arthritis will only be mildly affected, simple and local treatment and the use of the safest drugs possible may be all that is recommended. If your arthritis does progress there are now a number of different drug treatments available.

Assessment

The first steps in deciding when to treat and which treatment is best for you will be taken when your specialists have assessed your condition[2]. The members of your team will examine your joints to see how they are affected; you may also have x-rays and blood tests as part of this assessment. With this information your team will be able to make a prognosis. Damage to your joints on x-rays or high inflammation markers on your blood tests can indicate a greater likelihood of damage in the future and so you may benefit from more treatment. Psoriatic arthritis is very variable; a small number of people (5%) have a very

severe form but the majority have milder patterns[3]. There has been a lot of work carried out recently on the genetic predisposition of psoriatic arthritis, but doctors are not yet in a position to use genetic tests to make treatment decisions.

Treatment options

There are a wide range of treatment options available[2,4-6]. These are generally ranked by potential side effects (a non-intentional effect that can occur from a treatment). Treatment is considered in a stepwise fashion. This allows people to climb this escalation (increase) of treatment in a way that means starting with the least intrusive therapy that will control their disease (and symptoms) with the minimal risk of unwanted side effects and may include:

Non drug:

- physiotherapy (restore movement and function)
- occupational therapy (rehabilitation and adaptation)
- podiatry (foot, ankle and lower limb)
- orthotics (devices).

Medical therapy: [4,5]

- analgesics (painkillers)
- non-steroidal anti-inflammatory drugs (NSAIDS)
- steroids
- disease modifying anti-rheumatic drugs (DMARDS)
- biologic drugs.

Surgical therapy: [7]

- operations such as joint replacement (arthroplasty).

Treatment considerations

Treatment has two main goals: first to improve your symptoms, such as reducing pain, stiffness and fatigue; and second to prevent damage to your joints.

Treatments such as physiotherapy, exercise and education about psoriatic arthritis are likely to benefit almost everybody with the condition, though research in this area is very limited. Importantly, because these are not drug treatments they do not have the potential for side effects.

Drugs used to treat any disease carry the possibility of side effects, some of them mild but some maybe serious. The treatments used for rheumatic diseases are no exception. Even a milder drug from your pharmacist without prescription, such as aspirin or ibuprofen, can cause indigestion and/or gastrointestinal bleeding (such as stomach ulcers)[8]. The more powerful anti-inflammatory drugs, which are only available on prescription, also have a risk of side effects, particularly stomach ulcers. Other drugs may have to be given alongside, to try to prevent these side effects[8]. Your team will therefore try to find a balance in your therapy to give you the mildest treatment, with the fewest potential side effects, that will help manage your symptoms and disease.

The newer drugs, such as biologics, have and hopefully will continue to revolutionise the treatment of rheumatic diseases, including psoriatic arthritis, enabling many patients to lead a normal and relatively pain-free life. These more powerful drugs are not curative but may

suppress the disease to a significant degree, for example preventing flares from occurring and preventing or delaying long-term damage to the joints. Their side effects have the potential of being more severe and can include damage to the bone marrow, kidneys, liver and skin. Biologic drugs therefore should only be prescribed after discussion between patient and doctor so that the risks, benefits and possible impacts are fully understood.

A partnership

Deciding which treatment is best for someone with psoriatic arthritis is not just a specialists' decision based on which treatment is best. Treatment needs to be tailored to each individual person and will be a balance of what therapy is most likely to improve the symptoms and disease and what each person's thresholds are for taking medication and the risks of potential side effects. This will be different for each person with psoriatic arthritis but the right decision will be possible through active discussion with the team looking after the individual.

People with psoriatic arthritis should be prepared to ask questions of their team during consultations and should equally be prepared to take decisions for themselves as to whether they will or will not accept treatment for their condition.

Reviewing treatments

Whatever treatment is decided on, it should be reviewed on a regular basis. How often you need to be reviewed depends on the treatment you have been given and should be discussed with your doctor. At your reviews your team will discuss your symptoms with you, examine your joints and may ask for blood tests or x-rays to reassess your condition. In this way the team can check the treatment is working and does not need to be changed.

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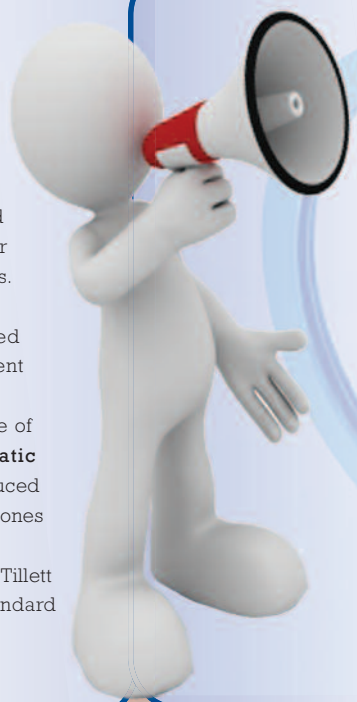
This article is taken from an updated version one of our popular free information leaflets, **Psoriatic Arthritis: When To Treat**, which was originally produced in 1993 and published in the first edition of Skin 'n' Bones Connection.

The new version has been updated by Dr William Tillett as part of our membership of the Information Standard scheme.



Our thanks to Dr William Tillett, who reviewed and revised the booklet using the latest research and guidelines.

This information is available as an 8-page booklet with expanded sections which include planning to treat, assessment, treatment options and treatment considerations.

If you would like a copy of the booklet then please contact us.

info@papaa.org
01923 672837
www.psoriasis-shop.org
www.papaa.org

Four years ago the Medicines and Healthcare products Regulatory Agency (MHRA) introduced the opportunity for patients to report side effects (adverse drug reactions - ADRs) from drugs directly to the agency via the previously established Yellow Card Scheme. It continues to be vitally important for patients to alert the agency about their suspicions or consequences of treatments.

Drug side effects

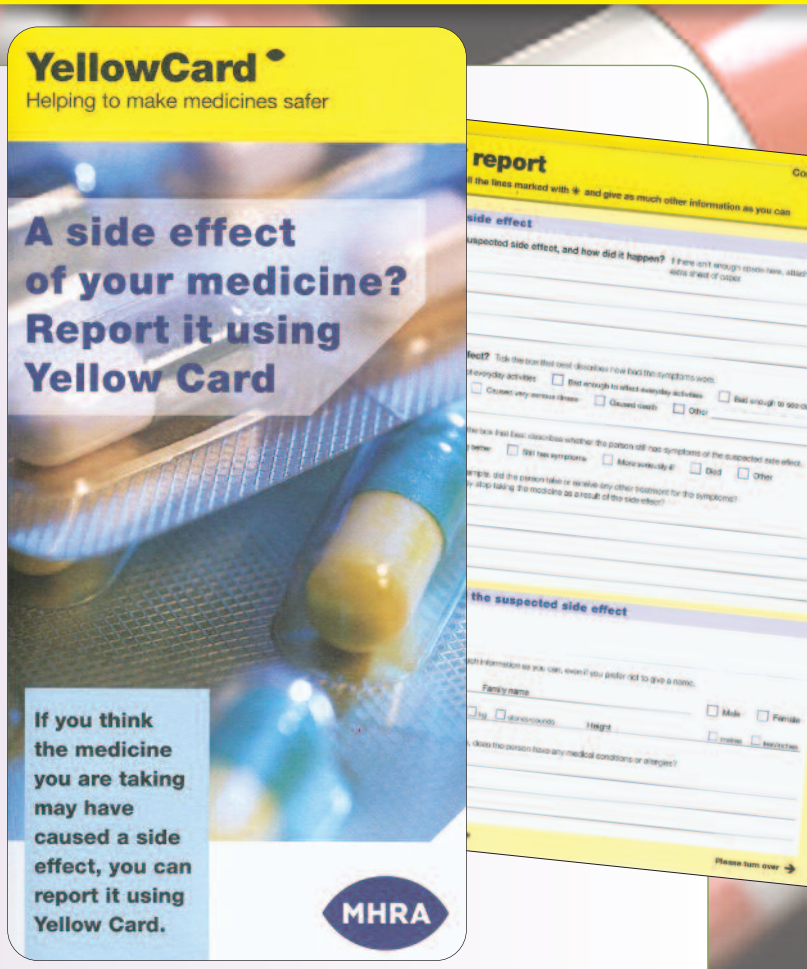
The Yellow Card Scheme is run by the MHRA and the Commission on Human Medicines (CHM), and is used to collect information from both health professionals and the general public on suspected ADRs to a medicine. Its continued success depends on the willingness of people to report suspected ADRs.

The agency collects Yellow Card reports from anyone from the UK on both licensed and unlicensed medicines, including:

- **prescription medicines**
- **vaccines**
- **over-the-counter (OTC) medicines**
- **herbal remedies**
- **swine flu antiviral medicines (Tamiflu or Relenza)**
- **swine flu vaccines (Pandemrix, made by GSK, or Celvapan, made by Baxter).**

All medicines can cause unwanted ADRs in some people. Many ADRs are mild, but some can be serious and even life-threatening. Occasionally ADRs can appear after a person has stopped taking a medicine.

You may ask "why are these ADRs not already known?" Some ADRs are not always seen in small clinical trials and it takes many people to have taken the medicine for a long time for these to become evident.



Sometimes, it can be difficult to tell whether a symptom is an ADR of your medicine, or something else. Even if you are not sure you can report the symptoms via a Yellow Card as it might not have been noted before.

The risk (potential of ADRs) versus the benefit (getting better) of any treatment are key considerations when embarking on a course of therapy. For some the list of ADRs contained within the in-pack patient information leaflet (PIL) will be of great concern, but improving symptoms and feeling better may outweigh such concerns.

Remember that healthcare providers are there to help you understand the benefits of a course of treatment, but should always take into account your concerns regarding ADRs and any long-term risks. If you are unsure or worried about ADRs talk to your doctor, even if the product you are taking has been bought without prescription or is a herbal remedy.

You can report ADRs by completing the Yellow Card form, which should be available at your doctor's surgery or pharmacy. Alternatively you can report via the internet at www.yellowcard.gov.uk

Gene linked to psoriasis

Scientists led by Washington University School of Medicine in St. Louis have identified the first gene directly linked to the most common form of psoriasis.

The research shows that rare mutations in the CARD14 gene, when activated by an environmental trigger, can lead to plaque psoriasis. This type of psoriasis accounts for 80% of all cases and is characterised by dry, raised, red patches covered with silvery scales that can be itchy and painful.

The new findings also indicate that mutations in CARD14 can be involved in the pustular form of psoriasis and in a debilitating arthritis linked to the psoriasis. The discovery may lead to more effective, targeted therapies for plaque psoriasis and other forms of the disease.

The research was published in May 2012 in two separate papers in The American Journal of Human Genetics.

''We have searched for almost two decades to find a single gene linked to plaque psoriasis,'' says the senior author of both papers, Anne Bowcock, PhD, professor of genetics. ''Individually, the rare mutations we have found likely confer a high risk for the disease, and we think they will be important in the search to find new, more effective treatments.''

Although psoriasis has long been thought to be caused by an overactive immune system, the genetic pathway uncovered by the scientists points to defects in the skin as the main culprit of the condition and to immune cells as secondary players.

Now the researchers want to find out how common the altered pathway is in the different types of psoriasis and in patients with psoriatic arthritis. Their work suggests that in at least some patients with different forms of psoriasis, this pathway is the same.

Like other common diseases, psoriasis runs in families and has been thought to have a genetic component, but it's been difficult to pin down the genes involved. That's because common variations in genes likely contribute very little to the overall genetic risk of the disease, and mutations that substantially increase a person's risk are so rare they have been impossible to find.

Using the latest DNA technology to sequence all of a patient's genes, Bowcock and her colleagues uncovered a rare CARD14 mutation in a large family

of northern European descent in which plaque psoriasis was prevalent. They also found the mutation in the one-third of family members who had developed psoriatic arthritis, suggesting that the same rare mutation can play a role in both conditions.

The scientists also identified another rare CARD14 mutation in an extended family from Taiwan that had a large number of plaque psoriasis cases.

But mutations in the gene do not only occur in families with a genetic predisposition.

The researchers, including the papers' first author Catherine Jordan, an MD/PhD student at Washington University, also found a CARD14 mutation in a 3-year-old girl with a severe case of pustular psoriasis, a rare form of psoriasis. Neither of the girl's parents had mutations in CARD14, indicating that the rare mutation was not inherited but had occurred spontaneously.

Gene linked to psoriasis

Psoriasis typically develops after an environmental trigger, which can include an infection, such as strep throat, or injury to the skin, including a cut or bug bite. Certain medications, smoking and heavy alcohol consumption are also triggers.

The young girl, from Haiti, developed psoriasis in infancy, like some members of the family with origins in northern Europe.

''This is significant because it tells us that CARD14 mutations alone are enough to lead to psoriasis, possibly after an early trigger such as an infection,'' Bowcock explains. ''You don't need anything else. This really highlights the importance of finding rare mutations for common diseases like psoriasis.''

The researchers also found 15 other rare mutations in CARD14. In a finding that is statistically significant, the mutations were more common in more than 6,000 patients with psoriasis compared to 4,000 healthy controls.

Psoriasis affects the life cycle of skin cells, causing them to mature rapidly in just a few days and accumulate to form thick, scaly patches. Interestingly, in psoriasis patients with CARD14 mutations, the researchers found the gene's activity was increased in the skin's upper layers, which may explain the flakiness that characterises the condition.

''Now, we have a much clearer picture of what is happening in psoriasis,'' Bowcock says. ''And with all kinds of new therapeutic targets that lie within the CARD14 pathway, the field is wide open.''

Collaborating institutions include The Rockefeller University, Academia Sinica in Taiwan, Baylor University Medical Center, National Institute of Arthritis and Musculoskeletal and Skin Diseases and the National Institute of Allergy and Infectious Diseases, both at the National Institutes of Health (NIH), National Taiwan University Hospital and National Taiwan University College of Medicine, University of Michigan, University of Utah School of Medicine and the University of California, San Francisco.

REFERENCES

Jordan CT, Bowcock AM et al. Rare and common variants in CARD14, an epidermal regulator of NF-kappaB, in psoriasis. The American Journal of Human Genetics. May 4, 2012.

Jordan CT, Bowcock AM et al. PSORS2 is due to mutations in CARD14. The American Journal of Human Genetics. May 4, 2012.

The scientists showed that in specialised skin cells called keratinocytes, mutations in CARD14 increase the activity of NF-kappaB, a protein that turns on genes. This protein increases the production of certain signaling molecules that attract inflammatory cells to the skin, unleashing a vicious cycle of inflammation that is so notable in psoriasis.

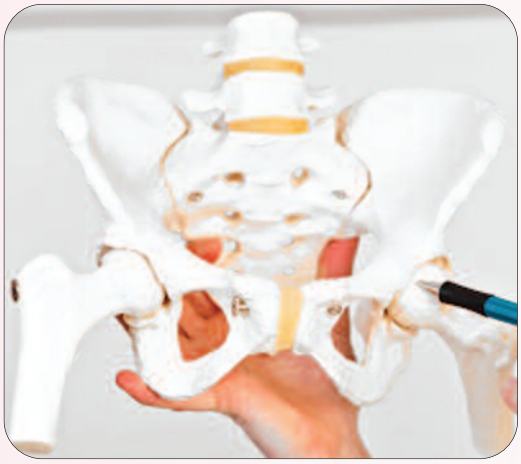
SOURCE:

Press release

Washington University in St. Louis

Metal on metal hips

The Medicines and Healthcare products Regulatory Agency (MHRA) recently issued updated advice to surgeons that patients with a particular type of metal-on-metal hip replacement should be monitored annually for the life of the hip replacement. This updates previous advice from April 2010 that patients with this type of hip replacement need only be monitored for a minimum of five years after their operation.



The updated advice is included in a new MHRA Medical Device Alert that has been issued to clinicians for the management of patients with these hip implants to minimise the risk of having to undergo further surgery to correct complications.

An expert advisory group was set up by the MHRA to look at the management of patients with soft tissue swelling associated with metal-on-metal hip implants. This group meets regularly to evaluate new scientific advice and observations from clinicians. This updated advice is based on updated evidence that patients with hip replacements with a head diameter of 36 millimetres or more need to be monitored every year.

Monitoring advice for patients with other hip implants, including other metal-on-metal hip replacements with a head diameter smaller than 36 millimetres and metal-on-metal hip resurfacing devices, has not changed.

Dr Susanne Ludgate, clinical director of the MHRA, said:

"Most patients with metal-on-metal hip replacements have well functioning hips and are at a low risk of developing any serious problems.

"As a precautionary measure we are updating our patient management and monitoring advice to surgeons and doctors because this particular type of hip replacement has a small risk of causing complications in patients. By monitoring patients every year, these complications will get picked up earlier and more complex surgery on the patient can be avoided.

"The MHRA was the first regulatory agency in the world to issue advice to clinicians about metal-on-metal hip implants in April 2010 and we are continuing to closely monitor all the latest evidence about these devices. If patients have any questions, they should speak to their orthopaedic surgeon or doctor."

Joe Dias, president of the British Orthopaedic Association (BOA) said:

"The safety of our patients is always our first concern. The British Orthopaedic Association welcomes the publication of this updated advice from the MHRA. We will continue to work closely with the MHRA to provide further advice on this matter as new information becomes available."

If you have any concerns about replacement joints talk to your doctor or surgeon.

www.mhra.gov.uk

Currency and skin allergies

The Royal Mint is introducing nickel-plated steel coins to replace the current versions, which contains 75% copper and 25% nickel, in response to the rising cost of copper.

Some dermatologists have raised fears that the new 5 and 10 pence coins being introduced could cause skin problems.

Experts from St John's Institute of Dermatology and the Royal Hallamshire Hospital in Sheffield have warned there have been no health checks on the new coins, and there could be a financial implication for the NHS due to increased visits to doctors by people affected.

Calling for the government's chief scientific adviser, Sir John Beddington, to look into the matter, they say: 'Considerable evidence supports these concerns, which have not been assessed by the Treasury.'

Professor David Gawkrodger, University of Sheffield, said: ''It is a theoretical concern. In comparison, in Sweden its central bank, the Swedish Riksbank, has recently concluded that nickel-plated coins pose unacceptable risks to health.''

It's estimated that £10 million a year could be saved by the changes in the metal content, but 10% of the population, particularly women, are affected by nickel allergy.

A spokesman for the coin manufacturing body Royal Mint says that although there have been no specific health checks the move meets with all existing guidelines.

Discontinuation of Xamiol®

From May this year, the gel formulation of calcipotriol/betamethasone dipropionate called Xamiol® for scalp psoriasis has been replaced by Dovobet® gel, which contains the same ingredients as Xamiol® but has dual indication for both body and scalp. The manufacturer says that the decision is "...to avoid patient confusion..."

Remember that Dovobet® products are a combination of a vitamin D analogue and a potent steroid and the guidance about amount and length of time they are used should be carefully followed.

Dovonex pack size change

The same manufacturer has also decided to replace 120g tubes of Dovonex® (calcipotriol) ointment with smaller 30g tubes. It was stated that this was a commercial decision. All versions of the cream formulation were discontinued last November.

If you are concerned or indeed confused about changes or the availability of your prescription, talk to your doctor. There are other products available for the treatment scalp and skin and your doctor will be able to advise you appropriately.

Letters

Q Dear PAPAA,

I wonder if you could help me! I'm affected by psoriatic arthritis and am interested in going away to get some treatment. I've heard that the Movenpick Resort and Spa in the Dead Sea is a good option, although you need to be there for at least 4 weeks to benefit from treatment. I wonder whether you offer any escorted trips to destinations that offer treatment for arthritis as I would prefer not to travel alone, partly to keep the cost down than travelling independently.

If you have any information about possible trips I would be very grateful to hear from you.

Yours ET

A Dear ET

We do not get involved in organising trips, but there are a number companies that offer specialist packages to the health resorts; one such company is called VIP Health Holidays (www.viphealthholidays.co.uk) but there are others. It might be worth looking at the Dead Sea tourism website, (www.deadsea.co.il), it's also worth checking with the Foreign Office regarding safe travel to/within Israel (www.fco.gov.uk/en/travel-and-living-abroad/travel-advice-by-country/)

There are also other spas that offer similar services; some of these are in Eastern Europe, but you would need to check for safety etc. More established places within Europe are also available such as Clinic Mirak in Fuertaventura(www.clinicamirak.com) or the Blue Lagoon in Iceland (www.bluelagoon.com).

As a word of warning, the scientific evidence is very thin regarding benefits from such places as the Dead Sea etc. As it is difficult to separate the benefits of the water from just being on holiday in a warm climate. Also, they do tend to be more expensive in comparison with a holiday in a warm country.

If you do take a trip let us know how you got on and wse'll print your story as I'm sure other readers will be interested in your experiences.

Yours PAPAA

Q Dear PAPAA,

I wonder if you could let me have any information about psoriasis on the scalp. I am in my forties and this condition arose a few years ago. At first the doctor was not sure what it was but my father had psoriasis and apparently it can be hereditary. I have been using medicated shampoo and also steroid scalp lotion, both of which are quite effective. My biggest concern is in using these products over a long period and what effect it will have on my hair. I do not want to be bald when I reach 60.

Yours PB

A Dear PB

As the term suggests, scalp psoriasis is psoriasis involving the scalp. It is common and approximately half of all people with psoriasis have it on their scalp. It can be particularly difficult to treat and usually requires specifically formulated medicines. Psoriasis in the scalp forms in the same way as in other parts of the body but the effect of the hair is to trap the scale and stop it being rubbed away as it is, for instance, with psoriasis on the elbow. The result is that the scale can quickly build up causing a thicker plaque which becomes more difficult to treat. This difficulty is compounded by the hair which also acts as a physical barrier, obstructing the application of creams and ointments to the affected skin.

A lot of product treatments will contain salicylic acid, known as a keratolytic. This ingredient aims to loosen psoriasis scales so they can be washed away more easily. This ingredient will be contained in both over the counter, OTC, and prescription products mostly found in shampoos and soaps. It should be noted that treatment with high concentrations of this ingredient can cause irritation and if used over large areas of skin the body may absorb it, leading to the weakening of hair shafts, causing them to break and leading to temporary hair loss. Hair should return to normal after stopping the treatment. Such products may be easier to apply at night and the head covered with a shower cap to avoid messiness. It's also more convenient as they can be time-consuming at the beginning of the day before going to work. ***Yours PAPAA***

Q Dear Papaa,

I am writing to you after reading an article in a women's magazine on psoriatic arthritis. I am 37 years old and have suffered for the last 5-6 years with psoriasis and have tried conventional and alternative treatments. I have suffered for many years with bad pain in my bones especially when I have been doing physical jobs etc. I am now unable to mow the lawn for example as the next day I can barely walk. I don't know if this is connected to my psoriasis or not but I would be very interested in some information.

Yours UA

A Dear UA

If you suspect you have psoriatic arthritis it is a good idea to see your doctor, particularly if you a history of psoriasis. Your doctor should be able to tell you if it is connected to your psoriasis, if not a referral to a rheumatologist, might be considered. Not everyone with psoriasis will get psoriatic arthritis; only about 10-20% of people with psoriasis will get the associated arthritis and in most case the condition very mild.

Yours PAPAA

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

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

Q: Have you ever experienced any symptoms relating to your psoriasis or psoriatic arthritis that have never been explained or resolved?

A: "I get lethargic. I can be OK for days or weeks then feel like I've been hit by truck for up to 2 days, convinced it has something to do with the two. Haven't seen a dermatologist since I've had it under control, but I often wonder!"

"I feel fatigued every day..."

"Coated sore tongue and sore gums came whilst I was taking methotrexate, now been off it for two months and it's still the same. And yes fatigue big time!"

"Fatigue and breathlessness, kind of air hunger like needing to yawn all the time."

"Fatigue and ulcers on tongue."

"Infected teeth, fatigue, heavy limbs and mouth bleeds on methotrexate, also why did arcoxia work for only 2 days ...perhaps I need to be patient?"

Q: *If you could change one thing about having psoriasis and or psoriatic arthritis; what would it be?*

A: "That people would realise having psoriatic arthritis is more than pain in your joints & how it changes your life."

"Psoriasis is one of those diseases that doesn't raise a concern with those who don't have it! Everyone knows someone who has it but nobody seems to be aware of psoriatic arthritis and its effects on the sufferer. I would raise awareness of psoriasis and psoriatic arthritis. Psoriasis can become life threatening!!"

"I totally agree. I'd raise awareness and improve my GP's understanding around the condition and how it impacts on a person. It is more than joint pain, it impacts on every part of your life.... emotionally and physically..."

" I've just had a return to work interview after my first major flare-up, and I have had a job to try and explain how it feels. You can't explain it to someone who doesn't suffer with it."

" Rebecca, I've had the same experience, they just thought I was skiving. In the end I printed out some articles about my condition and gave it to them. My pet hate is when someone says "you are too young to have arthritis, Oh I have it in my knees" they have no idea!!!"

"To find an immunosuppressant that doesn't upset my stomach"

"The pain! It's taken over my life and I can barely walk."

"I would love to lie down and rest without feeling like I have toothaches in my bones."

"I would love a normal body temperature, no chills or sweating."

" I would like to raise awareness of psoriatic arthritis and make people more aware of the impact on our lives, indeed our families lives. A day without any aches or pain would be great too!"

"If I could change one thing about having it? Not having it comes to mind!"

"Hands down, awareness and understanding of the disease. I'm surrounded by ignorant people who have flat out called me a hypochondriac because they've never been around me during a major flare-up or felt what I feel when I push myself through a task to attempt to keep as normal a life as possible. I'd also like the huge flakes in my hair to disappear. Those are the only plaques I have that I can't really cover up or hide unless I wear a hat."

" I would change the fact that there is no cure!"

Q: *Does your psoriasis or psoriatic arthritis regularly flare? If so, have you noticed what triggers the flare?*

A: "The worst flare for me comes from being in the sun as I have PLE and it sets the immune system off. Second is stress and overdoing things, not getting enough rest."

"Sadly, my mother in law..."

"I've noticed when I get flare-ups, but I can never pin down why it happens. The last time I had a flare-up was about 3-4 weeks ago and I still have no idea why it happened. On the bright side, I did notice that both my joints and my skin flared up at the same time (something which I had not actually noticed with such clarity in the 12 months since I got diagnosed with arthritis)."

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 via the articles link on the 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 article section.

Marketplace

Once again we are grateful to our readers who have sent us information about products which they have found useful. The **lotion applicator** is designed to apply cream and massage your skin at the same time. Simply remove the top of the applicator and fill with cream or lotion.

Rotating balls ensure even distribution.

Handle length 45cm (18'')

*Available from various outlets, including: OT Stores and Handy Healthcare. Prices start at £11.49**

A similar device called the **roll easy lotion applicator** massages the body while applying ointments, creams, lotions and medications. The product comes with 2 different massage rollers that are easy to use and change. The inverted roller hugs the body's natural curves and can be used to apply lotions to the arms, legs and neck. The round roller is ideal for use on the back. A pivoting, rotating head on the handle allows the rollers to be used at any angle and to cover even the hardest to reach areas. Handle folds for easy storage and travel.

*Available from various outlets, including: the Disability Warehouse, Amazon online and Living Made Easy. Prices start from about £19.00**

Contact details for the above products:

OT Stores
www.otstores.co.uk 0845 260 7061

Handy Healthcare
www.handyhealthcare.co.uk 01253 826622

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

Living Made Easy
www.livingmadeeasy.org.uk 0845 130 9177

*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.

Psoriasis 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.

Are you on Facebook or Twitter?

If so why not help us to develop our profile?

To get to our pages click the link from the 'About us' page on our main website www.papaa.org or you can just search for us on **Facebook, or on Twitter and look for @PsoriasisInfo** and then follow us.

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.