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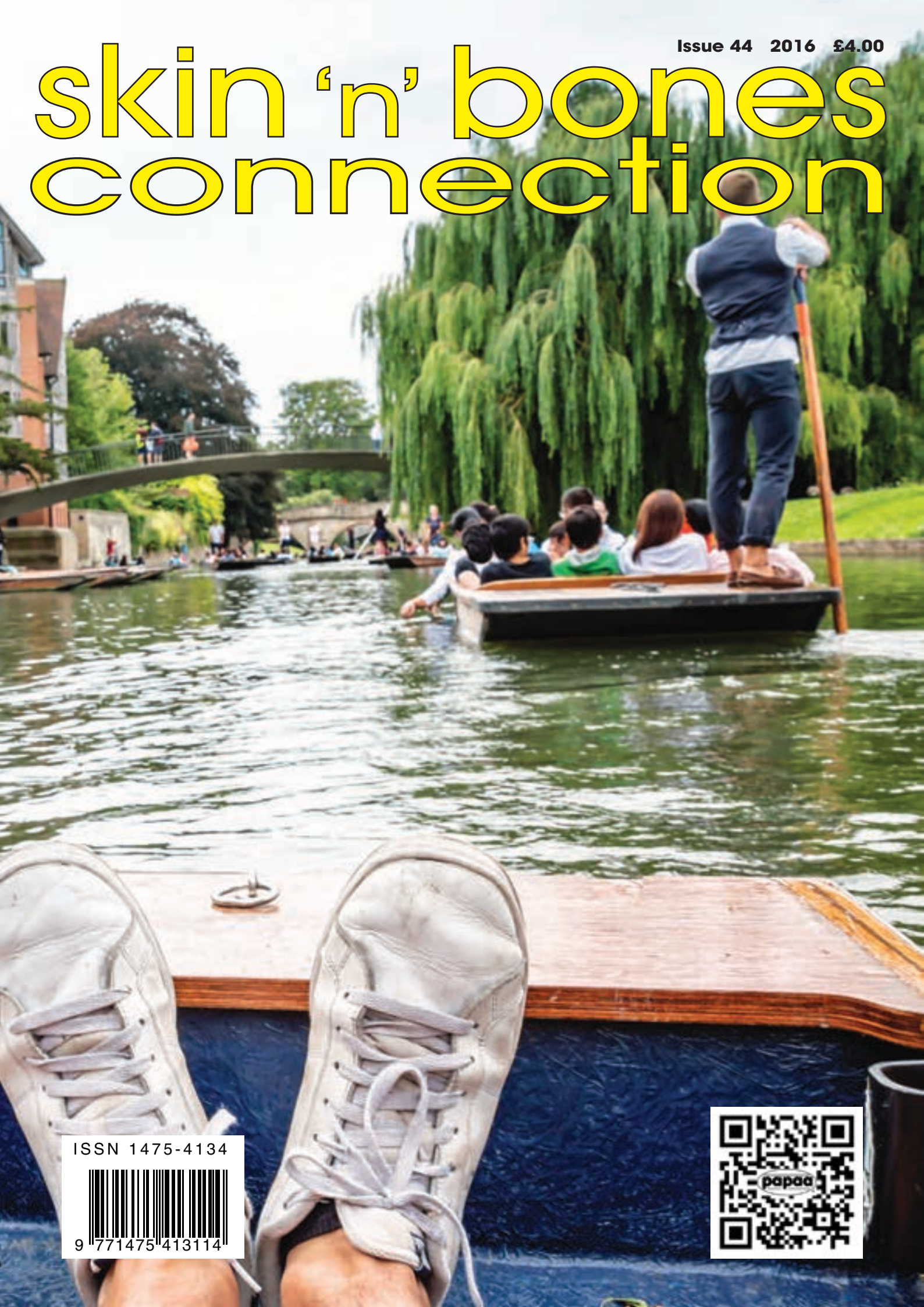
skin 'n' bones connection



ISSN 1475-4134

Dear Reader

At the recent patient evening held at Addenbrooke's Hospital reported on page 16, the theme was about taking time to engage with and understand the needs of people with psoriasis and psoriatic arthritis.

When you have a condition, understanding the extent of what has or will happen in the future helps to fill the vacuum that it creates through lack of knowledge or ignorance, which is explained on pages 6-9.

On page 3 we look at the basic starting point we all face, which is getting that all-important diagnosis. This is where the role of the patient is so important and helping to provide vital information about the symptoms and condition can help medical staff with the correct diagnosis and subsequent treatment.

Learning about others can also help and on pages 17-19 there are stories and opinions submitted, which add to the reality of living with a long-term condition.

Managing editor

Correspondence Address:
PAPAA
3 Horseshoe Business Park, Lye Lane, Bricket Wood,
St Albans, Herts. AL2 3TA
E-mail: info@papaa.org
Web: www.papaa.org
Tel: 01923 672837 Fax: 01923 682606

Production team:
Julie Chandler
Managing Editor

Artwork and Design
Macpro Design and Print Ltd., St Albans

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

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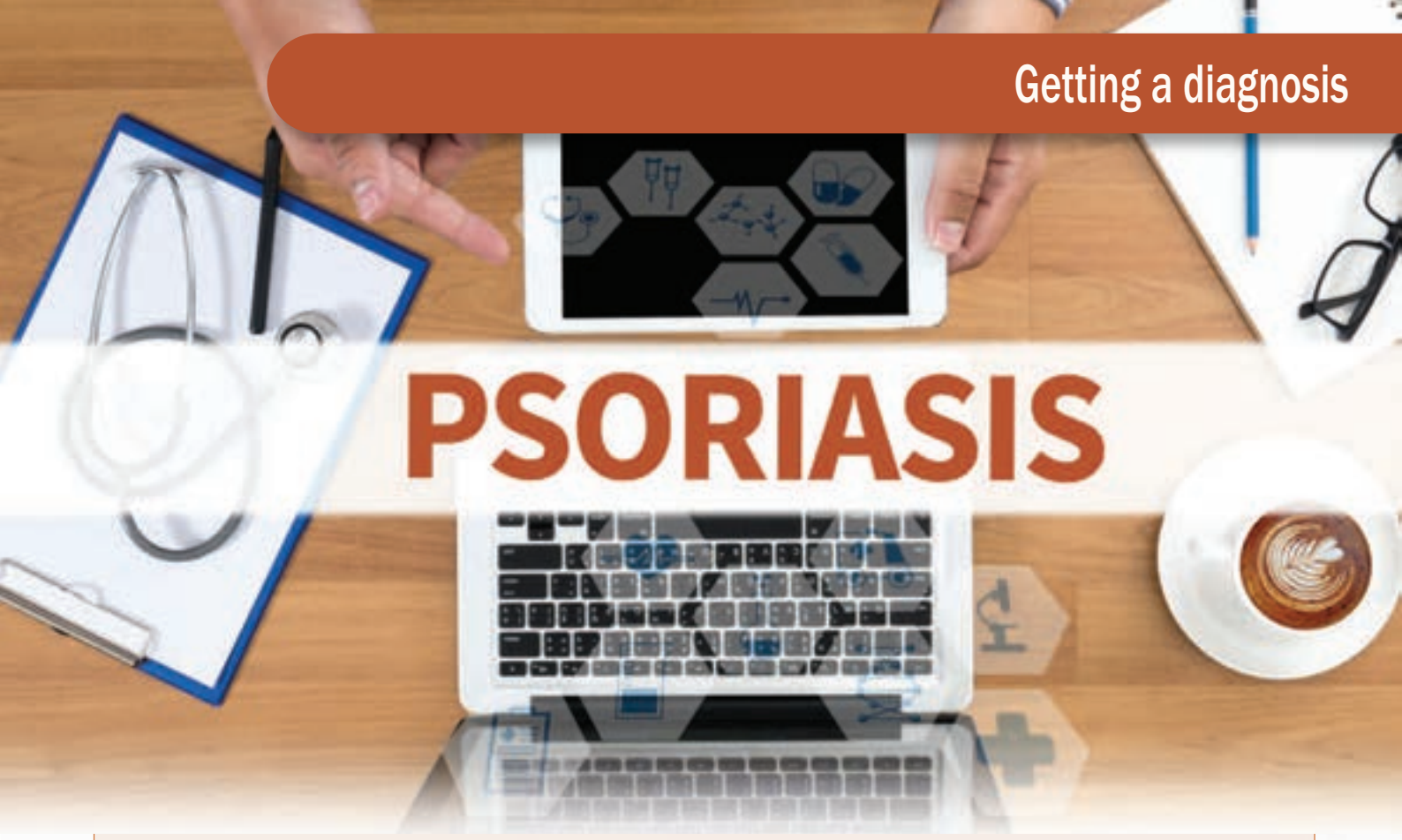
Punting on the River Cam in Cambridge

Image: Shutterstock ©JJFarq



When you develop skin or joint symptoms, it is easy to jump to the conclusion that you have a particular condition; this may be because you have read something in the media, on the internet, seen an advertisement, or a relative or a friend has a similar problem. Just because your symptoms are similar, do not assume that you have the same condition and therefore should be treated in the same way.

We all want to know what is causing a rash, a skin eruption or pain, but the cause is not always as obvious as it might appear. Getting the correct diagnosis and then treating appropriately is very important.

Skin

If you have noticed a change in the appearance of your skin it can be worrying, but there's often a simple explanation. The earlier you seek medical advice the easier it is to assess what may have caused the change; it could be an injury, allergic reaction or just a local irritation to clothing or activity.

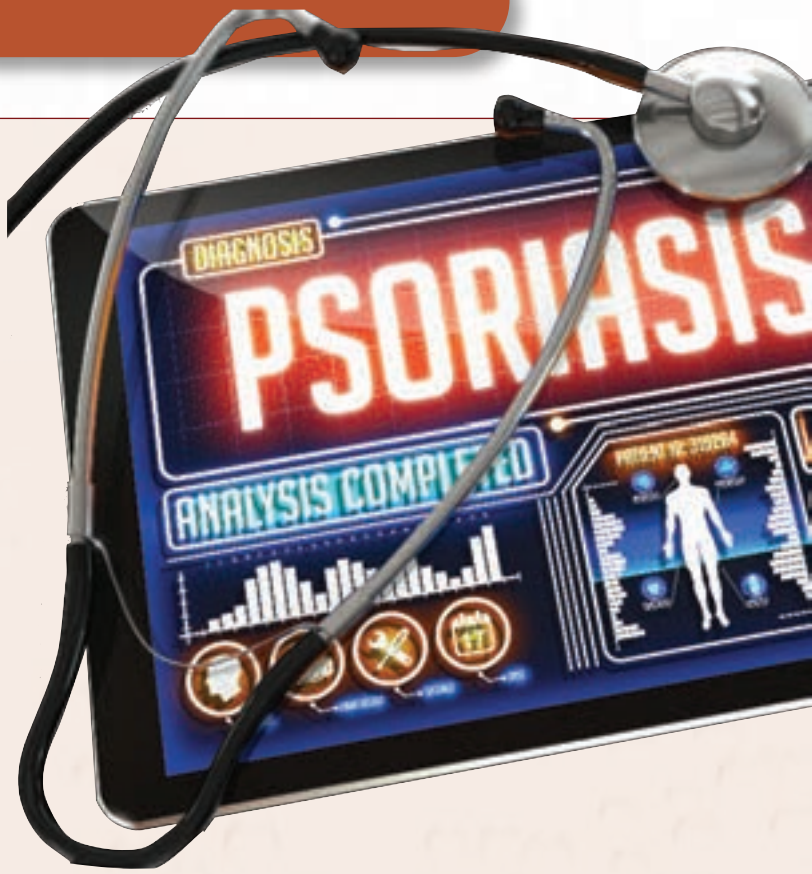
Assuming the worst may cause unnecessary worry and, likewise, dismissing it as nothing may be inappropriate too. Sometimes seeking advice from a pharmacist may help or booking an appointment with your GP might explain the cause and provide a simple solution; either way there is help available to support your needs.

Problems with your skin can be embarrassing, but remember your doctor has seen many cases before and early diagnosis can help to alleviate the anxiety and worry, not only for you, but also your family and those who care for you. Most skin problems can be treated effectively, but if you do not seek help, no one will know your skin is troubling you.

Diagnosing psoriasis

Diagnosis of psoriasis should be easy, and most cases are diagnosed upon visual examination by a GP. Not all psoriasis will be visible, so make sure your GP looks thoroughly, which will also help with determining severity and the appropriate course of treatment. You should try to remember when the symptoms started, if they appeared spontaneously or have developed over time. Try to recall if you had any other symptoms other than the rash, such as a cold, virus or sore throat, and whether you experienced any trauma or stress. The more information you can provide will help to determine what the condition is or what might have caused it.

Psoriasis can sometimes look similar to other skin conditions, such as seborrheic dermatitis



(seborrhea), dandruff, eczema, mycosis fungoides or pityriasis rubra pilaris, so in rare instances a small sample or scraping of skin (biopsy) might be sent for examination to rule out other conditions or to determine the exact type of psoriasis. It is important to get a correct diagnosis, so sometimes these further tests may appear unnecessary, but can provide valuable data and help reassure you.

Assessing severity

Once a diagnosis is established, assessing the impact and severity can be more challenging. The use of various diagnostic tools (usually validated questionnaires) will aid in the process. One such tool is PASI (Psoriasis Area and Severity Index), although this is unlikely to be used at primary care level. More likely, the BSA (Body Surface Area) will be used, as it is easier to estimate. The area of the hand, including fingers, is equivalent to 1% of the total body area, so do not be surprised if the percentage that your GP calculates appears to be lower than your own perception.

The use of quality of life surveys can provide useful guides to the impact and effect psoriasis has on daily life and mental wellbeing. Most commonly used are the DLQI (Dermatology Life Quality Index) and the HAQ (Disability Index of Health Assessment). If used correctly these tools can provide an ongoing evaluation of disease influence beyond the visual symptoms.

It is expected that once a diagnosis has been made that the process of assessment should follow the steps published by **National Institute For Health and Care Excellence (NICE) in guideline CG153, Psoriasis: assessment and management,** with the following recommendations being identified as priorities for implementation.

Assessment tools for disease severity and impact and when to refer for specialist care

For people with any type of psoriasis assess:

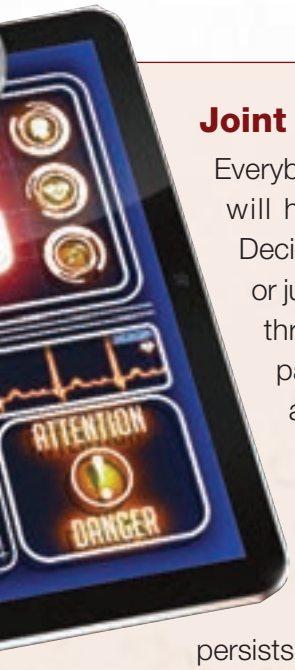
- **disease severity**
- **the impact of disease on physical, psychological and social wellbeing**
- **whether they have psoriatic arthritis**
- **the presence of comorbidities (other conditions).**

Following assessment in a non-specialist setting (GP/primary care), refer people for dermatology specialist advice if:

there is diagnostic uncertainty or

- **any type of psoriasis is severe or extensive, for example more than 10% of the body surface; area is affected or**
- **any type of psoriasis cannot be controlled with topical therapy; or**
- **acute guttate psoriasis requires phototherapy; or**
- **nail disease has a major functional or cosmetic impact; or**
- **any type of psoriasis is having a major impact on a person's physical, psychological or social wellbeing.**

If you are diagnosed with psoriasis, and not getting appropriate treatment, you may wish to remind your GP about what is recommended as best practice, as these guidelines are based on the best evidence available and designed to provide the best way of managing psoriasis for you and your GP.



Joint and muscle pain

Everybody at some stage in his or her life will have a pain in a joint or muscle. Deciding whether these pains are serious or just part of the rigours our bodies goes through can be difficult. Developing a pain or restricted movement can have a profound effect at any age, with fear and worries leading people to leap to the conclusion that it is a serious problem or the reverse and dismissing it as trivial.

If you develop any type of pain that persists for more than a few days it is worth seeking further assessment and advice. An

appointment with a GP may allay any worries or fears, and you should not feel that it is a waste of time to report your symptoms, as doctors are there to help you.

Diagnosing psoriatic arthritis

It might seem as though it should be easy to diagnose psoriatic arthritis. Many people, when they do get a diagnosis, will wonder why it was not obvious at the first appointment. However, there could be a number of reasons:

- **lack of awareness of the condition**
- **variable non-specific symptoms**
- **no visible psoriasis present**
- **lack of positive diagnostic test results (blood tests)**
- **no changes to basic x-rays and imagery.**

Although there are ways that can point towards psoriatic arthritis, for many people the condition tends to develop slowly with aches and pains often in the hands or feet with stiffness in the joints particularly in the morning, that then improves on movement. A family history of psoriasis could also provide a clue.

Age can provide another clue, as often the symptoms start between 20 and 30 years of age, which is not always the case for some other types of inflammatory arthritis.

Psoriatic arthritis can affect any joint; in some instances it can be just a single joint, which is swollen and painful for no obvious reason. Changes to the nails are also potentially a sign that might suggest psoriatic arthritis.

Clinical examination and the elimination of other conditions is often how many people end up with a diagnosis of psoriatic arthritis. This can be a frustrating process, with numerous tests and visits, along with medication that may not provide symptom relief.

If you think you may have psoriatic arthritis, it is important to try to provide as much information as you can to your doctor. Particularly the possibility of a link to psoriasis. This could be the key to unravelling the symptoms you are experiencing.

Useful links:
NICE Psoriasis Guideline
www.nice.org.uk/guidance/cg153

Psoriasis and psoriatic arthritis explained

Following a successful diagnosis of psoriasis and/or psoriatic arthritis, it is a good idea to understand the conditions and to learn what to expect. If you have psoriasis or psoriatic arthritis, or know someone with the conditions, the following explains the basics.

What is psoriasis?

Psoriasis is classed as a long-term condition but in medical terminology is referred to as a chronic condition, likely to persist for more than 3-months. For most people this will be for the rest of their life.

Psoriasis is inflammatory, with symptoms that include red, raised scaly patches known as plaques. In the UK between 1 and 3% of the population is affected. With 64 million people living in the UK, that could be around 1 and 2 million people with psoriasis. Therefore, it is very common and for most people very mild.

- Mild psoriasis (80% of people) is where there are a few patches that may need treatment but are not likely to cause problems and can be easily controlled.
- Moderate psoriasis (15% of people) is where more skin is involved and the condition widespread but again can usually be controlled with self-management under GP or nurse supervision.
- Severe psoriasis (5% of people) is where large areas are covered with psoriasis and the condition is becoming difficult to self-manage or is no longer responding to treatment. At this stage, referral to secondary care at a local hospital out-patient department or, in extreme cases, an in-patient stay may be felt necessary in order to provide optimum care and monitoring.

Any area of skin surface may be involved but plaques most commonly appear on the elbows, knees and scalp. Nail involvement is very common. It can be itchy but is not usually painful. Remember, although psoriasis is a chronic condition with no cure it can be controlled and go into remission (go away).

Who does it affect?

It affects men, women and children alike. It can appear at any age in varying degrees but usually between the ages of 10 and 30. The extent of disease varies enormously from a minute patch to large patches covering most body areas. Psoriasis can also run in families and much research is being done into the genetics of this disease.

It is known that the disease is multi-genetic and therefore children may not necessarily inherit psoriasis.

What happens?

Normally a skin cell matures in 21-28 days and during this time it travels to the surface, where it is lost in a constant, invisible shedding of dead cells. In patches of psoriasis the turnover of skin cells is much faster, around 4-7 days, and this means that even live cells can reach the surface and accumulate with the dead cells. This process is the same wherever it occurs on the body. There are many conditions that look like psoriasis. It needs to be understood that psoriasis is not contagious.

What causes psoriasis?

The exact cause of psoriasis is unknown, although it is known that genetic make-up plays a significant part. It is also known that psoriasis is the result of something going wrong with the immune system, which can be set off by certain trigger factors.

What is psoriatic arthritis?

About 30% of people with psoriasis may develop an associated arthritis called psoriatic arthropathy (PsA), which causes pain and swelling of the joints and connective tissue, accompanied by stiffness, particularly in the mornings. Most commonly psoriatic arthritis can affect your fingers, wrists, spine, feet, eyes (uveitis) or neck. You may at some time experience tender, inflamed muscles and tendons, especially around these areas. Movement in these areas becoming severely limited. Chronic fatigue is a common complaint linked with this condition.

Can psoriatic arthritis affect children?

As many as 12,000 children in the UK are affected by arthritis. It is known as juvenile chronic arthritis (JCA), of which there are three main types; Still's disease, polyarticular juvenile chronic arthritis and polyarticular onset juvenile chronic arthritis. Psoriatic arthritis is a minor subset of JCA and is uncommon.

Which joints are affected by psoriatic arthritis?

There are 78 major joints in the body and psoriatic arthritis can affect any one of them. Usually, however, certain joints are more likely to be affected (such as fingers and toes). Different patterns are found. Sometimes just one or two joints (such as a knee or ankle) are a problem but often several joints, both large and small and on both sides of the body, are involved. The number of joints affected is recorded as follows:

- **Monoarthritis** - one joint at a time
- **Oligoarthritis** - affecting two to four joints
- **Polyarthritis** - involves five or more joints simultaneously.

The main types of psoriatic arthritis:

- **Symmetric psoriatic arthritis:** affecting 50% of people with PsA; similar joints on both sides of the body are involved at the same time
- **Asymmetric psoriatic arthritis:** often mild, affects 35%. It doesn't appear in the same joints on both sides of the body
- **Distal psoriatic arthritis:** the ends of the fingers and toes, along with changes in toenails and fingernails of the digits affected
- **Spondylitis:** Pain and stiffness in the spine and neck affecting about 30%
- **Arthritis mutilans:** the most severe, affecting only 5% of people who have the condition.

Another way in which psoriatic arthritis can be recognised by a sausage-like swelling of a finger or toe, called dactylitis. This is caused by inflammation occurring simultaneously in joints and tendons. Painful heels and other bony prominencies can also occur and this is caused by inflammation where gristle attaches to bone.

What other areas are affected?

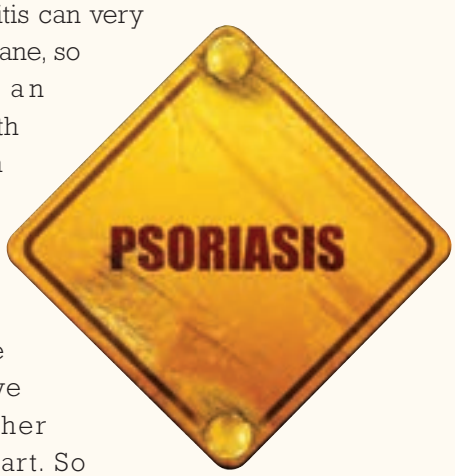
Apart from the skin, nails and joints, increased cardiovascular morbidity (state of being diseased or unhealthy) is considered part of psoriatic disease, as is the association with inflammatory bowel disease.

An itchy, red eye due to conjunctivitis is more common in people with psoriatic arthritis and some people occasionally develop a painful, red eye caused by inflammation around the pupil of the eye, which is called iritis or uveitis.

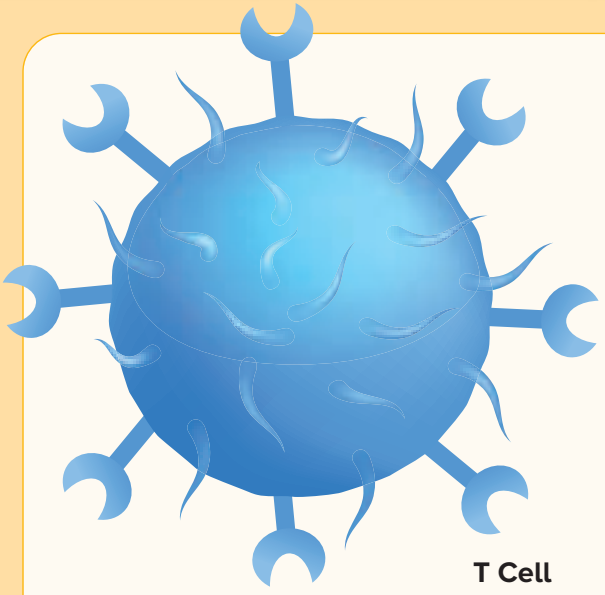
Anaemia (a shortage of red blood cells) may also be found but this is the result of long-term inflammation and is not a specific feature of psoriatic arthritis.

Common signs of psoriatic arthritis

Psoriatic arthritis can be elusive and difficult to pin down to some of the medical profession, and indeed, you may feel sometimes that you have become a hypochondriac, experiencing the odd pains in your finger, toe, back or wrist.



Psoriatic arthritis can very much wax and wane, so if you book an appointment with your GP for a nagging pain in your toe or elsewhere, by the time you see the doctor, the pain could have moved to another joint or body part. So don't worry, try to keep a



T Cell

mental note of any symptoms, aches and pains for a short while, then go to your GP.

The important fact to remember is that you must stress to your doctor that if you have psoriasis, no matter how small a patch there is, do inform the doctor of this because, psoriasis and psoriatic arthritis go together. This can be an important clue medically to diagnosing your condition early. The earlier the diagnosis, the better to prevent any unnecessary joint damage occurring.

Which comes first, the psoriasis or the arthritis?

In approximately 80% of cases, the arthritis will develop after the appearance of psoriasis. However, in about 20% of cases, the joint inflammation will come first.

What goes wrong with the immune system in psoriasis?

Your immune system is designed to protect you against infection and disease. It is made up of a number of white blood cells (T cells) that patrol the body in search of cells and proteins that should not be there. All your own cells have special identity tags to help your immune system recognise them. Sometimes, however, the immune system overreacts or even attacks parts of the body, which causes problems.

In psoriasis, T cells are put into action by mistake and become so active that they trigger other immune responses, which lead to inflammation and to the rapid turnover of cells which pile up on the surface of the skin, forming raised, red, scaly plaques. This inflammation can also affect the joints, causing psoriatic arthritis.

The exact mechanism that stimulates these T cells into their harmful behaviour is not known but a number of trigger factors have been discovered.

Is there a cure?

Unfortunately, not at the moment. However, much research is being done and in the last decade great strides have been made in understanding what goes wrong in psoriasis, so there is good cause for optimism. In the meantime there are a number of treatments that are effective in keeping the problem under control. The art of treatment is finding the best for each individual. There is no single solution that is right for everyone.

What is the genetic predisposition?

Genetic predisposition means an inherited tendency to develop the disease. Recent research has greatly increased our knowledge about how and what we inherit from our parents and the role played by genes. As our knowledge increases so does our appreciation of the complexity of the process. While it was originally hoped that a specific disease might be associated with a specific gene, it now appears that for many diseases that have a genetic component, including psoriasis, there are probably multiple genes involved in producing the sequence of events that results in the expression of disease. This is further complicated by the way these genes interact.

However, the evidence to support the belief that a genetic predisposition plays a major role in the cause of psoriasis can be summarised as follows:

- One third of people with psoriasis have a family member who is also affected
- There is an increased incidence of psoriasis in children when one or both parents have the disease. If both parents have psoriasis then the risk of children developing psoriasis is 75% and if one parent has psoriasis, the risk of children developing the disease is 15%. If a brother or sister (but neither parent) has psoriasis then the risk of other siblings developing psoriasis is 20%
- In twins, psoriasis is much more likely to appear in both identical twins than in both non-identical twins. This finding also confirms that more than one gene must be involved
- There is a higher than expected frequency of certain characteristics of blood cells in people with psoriasis and their close relatives. However, some people with psoriasis have no family history at all.

- It is important to understand that genetic predisposition does not mean a 100% guarantee that the disease will appear. Other initiating or trigger factors may act together with genetic predisposition to set the disease process in motion.

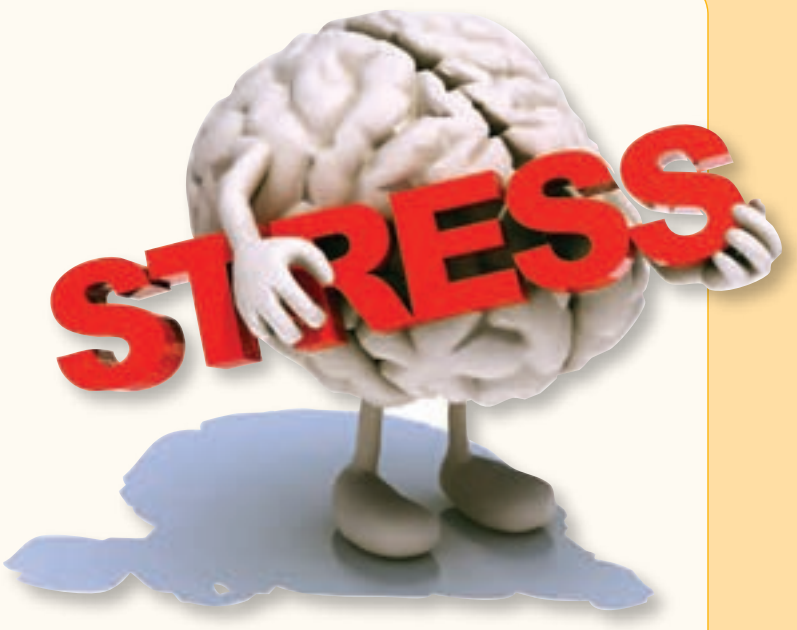
The triggers for psoriasis

Although the underlying cause stems from your body's immune system, the trigger factors that can make it worse or cause flare-ups include:

- **Cold and dry weather.** Such weather can dry out your skin, which makes the chances of having a flare-up worse. In contrast, hot, sunny weather appears to help control the symptoms of psoriasis in most people.
- **Stress.** Having psoriasis can cause stress and patients often report that outbreaks of symptoms come during particularly stressful times.
- **Some medications.** Certain drugs, such as lithium (a common treatment for bipolar disorder), drugs for malaria, and some beta-blockers (used to treat high blood pressure, heart disease and problems with heart rhythm), can cause flare-ups of psoriasis. Some common painkillers – called non-steroidal anti-inflammatory drugs (NSAIDs) – may also aggravate psoriasis, although they are still used in some people with psoriatic arthritis.
- **Infections or disease.** Certain infections, such as strep throat or tonsillitis, can result in guttate or other types of psoriasis. Psoriasis may worsen in people who have HIV.
- **Trauma to the skin.** In some people with psoriasis, trauma to the skin – including cuts, bruises, burns, bumps, vaccinations, tattoos and other skin conditions – can cause a flare-up of psoriasis symptoms either at the site of the injury or elsewhere. This condition is called Koebner's phenomenon.
- **Smoking.** Some experts think that smoking can worsen psoriasis.

Quality of life

It is widely accepted that psoriasis can severely affect an individual's quality of life, although for many the condition is mild and a mere inconvenience. The severity of the disease does not always relate to the severity of anxiety that an individual will have. The area where the psoriasis is located, such as the hands or face, can severely affect an individual's ability to work or lead to discrimination due to ignorance.



How do I live with psoriasis and psoriatic arthritis?

Learning to live with a chronic disease is an adjustment process, that can cause many problems. People often say that they feel a sense of mourning, for not being able to do the things you once did, with loss of confidence and self-esteem, can make you feel unattractive and have a negative effect on your life.

- Try to feel positive about yourself and concentrate on your good points
- Try to reduce levels of stress and anxiety
- Try to work out which trigger factors can bring your symptoms on and avoid them
- Talk to someone close, or write down your feelings to let them out - don't bottle things up
- Try to feel positive. Imagine yourself in control.

Learning more about the conditions and understanding how they affect you and your life will help you plan and adjust. Self-help, whether through mutual support or sharing your experience with others may help.

Useful sources of information:
PAPAA website: www.papaa.org
Targeted intervention for psoriasis: www.etips.org.uk

Psychological support not being met

Experts from an award-winning multidisciplinary team, the Severe Eczema and Psoriasis Team at St John's Institute of Dermatology, St Guys' and St Thomas' NHS Foundation Trust, recently warned that the true need for psychological support amongst dermatology patients is not being met.

The team recently won the first ever "BMJ Dermatology Team of the Year Award", up against excellent competition, for their commitment to holistic care - care which accounts for, and treats, the range of issues that come with having a skin disease, particularly the psychological impact.

Recognising that their standard approach to patients wasn't efficient enough at recognising patients in need of psychological support, the St. John's team rewrote the rulebook using a tripartite approach first developed by the IMPARTS* team led by Professor Matthew Hotopf. They developed a system whereby iPads are used to survey patients with pre-selected and validated questionnaires relevant to their condition, whilst waiting for their appointment. This information is then automatically uploaded to their electronic patient record.

The questionnaire results are then used to alert doctors to any potential emotional wellbeing issues and automatically suggest treatments or referral pathways that may be appropriate for them. In some cases there may be no need for psychological support. Those who do require help may be provided with self-help materials – such as the IMPARTS materials or the British Association of Dermatologists' Skin Support** website – or be offered a referral to a team psychologist or liaison psychiatry.

The team found that 71% of their patients, who were subsequently diagnosed with major depressive illness using the new system, and 88.6% with anxiety, were previously unrecognised as having mental health problems.

Professor Catherine Smith, consultant dermatologist within the Severe Eczema and Psoriasis team, said:

"This rigorous and systematic approach to providing holistic care within our team has reaped huge benefits for our patients, who previously might have had unrecognised morbidity. Prior to evaluating our service and introducing this new approach, we considered that we were already providing holistic care.

"Identifying the high needs of our patient population motivated us to fully integrate psychological support with treatment of the physical symptoms of skin disease throughout the visit to our service. We improved training for all staff, from our receptionists to our consultant dermatologists, and implemented internal care pathways that ensure the mental wellbeing of the patient is monitored and treated according to their needs. By taking this methodical approach we were also able to quantify and justify the need for a full-time clinical health psychologist on staff."

Dr Nick Levell, president of the British Association of Dermatologists, said:

"We are enormously proud of all the teams that were in the running for dermatology team of the year, and I am particularly pleased to see the incredible work that this winning team has put into achieving a parity of esteem between physical and mental health, something the BAD recognises as being hugely important for patient wellbeing. I hope that this will encourage other departments to reflect on their own work, and investigate ways in which they can improve."

The multidisciplinary team of specialists included consultant dermatologists, receptionists, clinical research and specialist nurses, a consultant rheumatologist, a specialist pharmacist, and a clinical health psychologist in collaboration with the King's Health Partners IMPARTS team.

ABOUT:

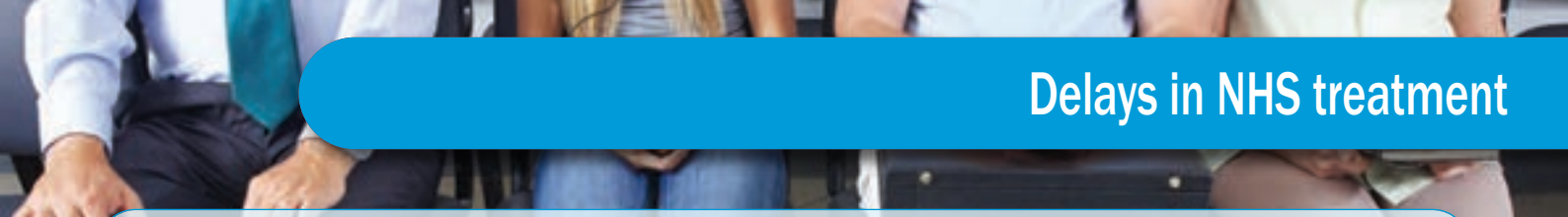
The British Association of Dermatologists is the central association of practising UK dermatologists. Its aim is to continually improve the treatment and understanding of skin disease.

For further information about the charity, visit www.bad.org.uk

***IMPARTS** stands for Integrating Mental & Physical healthcare: Research, Training & Services (IMPARTS) and is an initiative funded by King's Health Partners to integrate mental and physical healthcare in research, training and clinical services at Guy's, St Thomas's and King's College Hospitals, as well as South London and Maudsley NHS Foundation Trust (http://www.kcl.ac.uk/ioppn/depts/pm/research/imparts/index.aspx).

****Skin Support** is a psychological support website for people in distress due to skin conditions (www.skinsupport.org.uk). It is owned and managed by the British Association of Dermatologists.

Source:
British Association of Dermatologists



Delays in NHS treatment

Up to a million Britons are at risk of preventable, long-term disability and reduced life expectancy due to delays in referrals to specialist advice and treatment services, according to the most comprehensive audit of rheumatology services carried out across England and Wales.

The first weeks and months following the onset of rheumatic disease symptoms are known as the 'window of opportunity', and it is crucial that patients get appropriate treatment in that time period to maximise their chances of avoiding lasting complications. Early referral to, and assessment by, rheumatology services is therefore vital and the report reveals that for four out of five patients in England and Wales, this does not happen.

The National Rheumatoid and Early Inflammatory Arthritis Audit report was commissioned by the Healthcare Quality Improvement Partnership (HQIP) as part of the National Clinical Audit and Patient Outcome Programme (NCAPOP) and carried out by the British Society for Rheumatology (BSR). The report reveals that nationally just 20% of patients who see a GP with suspected rheumatoid and early inflammatory arthritis are referred to specialist services within the three-day limit recommended by the National Institute for Health and Care Excellence (NICE). For some health providers, this wait is over 20 weeks for a quarter of their patients. Nationally, fewer than half of patients who are referred are seen by a specialist within the three-week time limit recommended by NICE. For some providers, a quarter of patients are waiting more than 12 weeks.

The report reveals considerable differences in achievement rates for the standards across England and Wales. A 'postcode lottery' means that depending on where a patient lives, they are far more or less likely to access treatment at an early stage and hence prevent the disease becoming more advanced and life-shortening. For example, patients in Wales are half as likely to see a specialist within three weeks as those living in London.

The audit data points to several reasons for the delays in accessing services, including the overall number of rheumatology specialists needed to diagnose and treat the disease. The BSR calculates that consultant levels are 21% below Royal College of Physicians recommended levels, and the number of additional consultants needed is likely to increase as the demand for rheumatology services increases. The latest report also shows a link between numbers of specialist nurses and an ability to commence treatment in a timely manner and achieve treatment targets.

Research has highlighted a lack of awareness of the symptoms of disease and of the need for quick referral amongst GPs. Most patients will initially present to their GPs.

There are significant personal and societal costs linked with inflammatory and rheumatoid arthritis. These are some of the most common debilitating medical conditions in the UK. Around 10 million people have a form of arthritis, of which almost 700,000 have rheumatoid arthritis. Around 12,000 children suffer from juvenile idiopathic arthritis, the childhood equivalent disease. The arthritis can be so severe that those with the disease cannot bathe or dress themselves or perform simple tasks such as walking a short distance. Rheumatic conditions do not only damage joints but can also damage vital organs, including the lungs, heart, nervous system, kidneys, skin and eyes, if not adequately treated.

One third of sufferers will have stopped working within two years of onset, and half will be unable to work within ten years. Rheumatoid arthritis is a major cause of sickness absence and unemployment, and this is estimated to cost around £1.8 billion per year. It has been estimated that reducing work limitations and loss of work can save the UK economy around £31 million

Delays in NHS treatment

a year for rheumatoid arthritis alone. Patients are twice as likely to experience depression and have similar risks of cardiovascular disease as patients with diabetes.

The audit's recommendations include:

- Increase awareness amongst the general public of the symptoms of inflammatory arthritis and the need for quick treatment to prevent it progressing
- Increase GPs' awareness of the varied symptoms and in particular the need for referral within the NICE guidelines in order to maximise the efficiency of treatment programmes and prevent the disease progressing into more serious, later stages
- Analyse and understand variation in performance against the key standards
- Review the adequacy of specialist nurse provision, given the strong association between staffing levels and timely delivery of intensive treatment
- Support national audit data collection.

Clinical audit director Dr Jo Ledingham said:

"Inflammatory arthritis is a widespread medical condition with higher linked mortality rates than some cancers. But with appropriate and quick treatment the disease and its consequences can be controlled. GPs understand the need for speed when it comes to diagnosing and referring cancer patients, yet many still don't understand that they need to treat inflammatory arthritis with the same urgency.

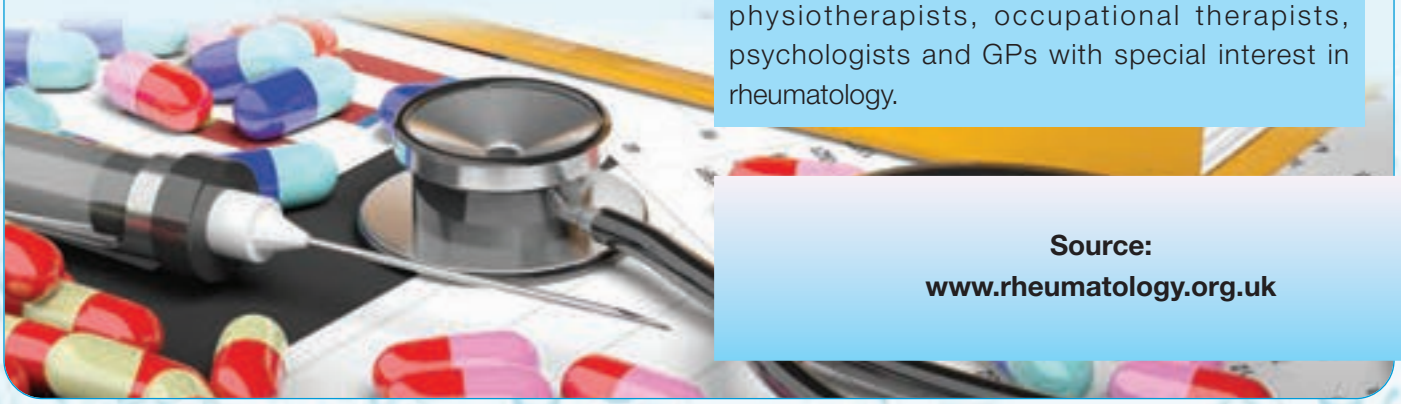
"Remission is a realistic aim with modern management, allowing patients to live a longer and more fulfilling life, benefitting themselves, their families, their employers and ultimately costing the government less in benefit payments and more costly drug treatment. Rapid access to specialist services is needed, however, to facilitate this. I hope this report serves as a wake-up call to everybody involved in referring, diagnosing, treating and commissioning services for inflammatory arthritis – from GPs to specialists. In particular, far quicker and more consistent referral and treatment times need to be achieved across England and Wales."

BSR president Dr Peter Lanyon added:

"It's now very clear from the consistency of the data that important variations in standards for people living with inflammatory arthritis still exist. This has implications for both primary and secondary care clinicians and commissioners. We all have a role to play in working towards reducing this unwarranted variation, at local, regional and national level. I would urge all those commissioning or delivering services to read the report in detail, reflect on the results, and decide individually and within respective teams what the implications are and what actions are required."

ABOUT THE BSR

The British Society for Rheumatology is the professional medical association for rheumatology and musculoskeletal medical and long-term conditions. Members are made up of the whole multidisciplinary team, including consultant rheumatologists, trainees, specialised nurses, physiotherapists, occupational therapists, psychologists and GPs with special interest in rheumatology.



Source:
www.rheumatology.org.uk

A study published in *Journal of Investigative Dermatology* has identified a potential therapeutic target for the treatment of psoriasis. The study shows that the TREX2 gene has a relevant role in the inflammatory response that develops during the illness. The research, led by researchers from the department of pathology and experimental therapeutics of the Faculty of Medicine and Health Sciences of the University of Barcelona and the Bellvitge Biomedical Research Institute (IDIBELL), contributes to increase the knowledge about this complex and multi-factor inflammatory disease and opens doors to the development of new therapeutic strategies.

The study also counts with the participation of experts from the Scientific and Technologic Centres of the UB (CCiTUB), the Institute of Predictive and Personalised Medicine of Cancer (IMPPC), Hospital del Mar, and Wake Forest University (North Carolina, USA).

In the study, the investigators examined levels of the gene in biopsies from people with and without psoriasis and assessed the development of the disease in normal and TREX2-deficient mice.

"The results show that TREX2 would have a relevant role in the DNA degradation on psoriasis epidermis, provoking the characteristic inflammatory response of this disease," remarked study author Concepció Soler.

The researchers observed that skin with psoriasis had high levels of TREX2 in keratinocytes.

''In our study, we highlight the essential role of TREX2 promoting DNA degradation and its consequent cell death of keratinocyte, influencing the skin immune response,''

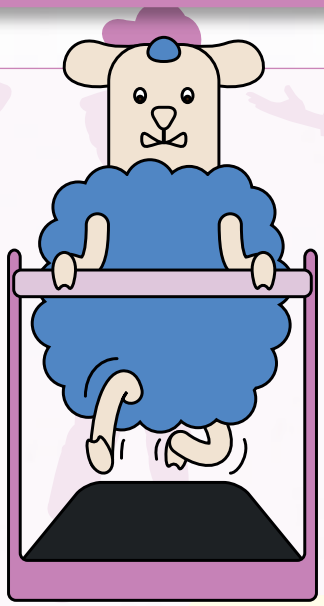
explained study author Joan Manils,

adding, ''The release of several signals by skin cells that are dying contributes to the creation and spreading of the chronic immune response and hyper-proliferation and irregular differentiation of epidermis.''

The results show TREX2 as a potential therapeutic target to tackle this disease with a different and more focused strategy. ''Most of the current treatments are aimed at blocking the action of the immune system and if they have good results, these treatments are chronic and involve the immune response of the sick person,'' said co-author Francisco Ciruela.

The next objective of the researchers is to decode the action mechanism of TREX2 in the development and maintenance of psoriasis, to design new therapeutic strategies for the treatment of the disease.

Source:
The University of Barcelona



The benefits of being physically active are far greater for those who are naturally unfit, according to scientists at the University of Glasgow.

In a study of almost 500,000 participants from the UK Biobank, the researchers found that the benefits of being physically active, including decreased risk of mortality and heart disease, were far greater for those with low levels of fitness or poor grip strength.

The study, which is published in *European Heart Journal*, found that those with high fitness or strength levels were at low risk of premature mortality and cardiovascular disease, whether they had high or low levels of physical activity.

A high level of fitness – the ability of the body to deliver oxygen to the muscles so that they can do work – and a high level of strength are both known to be associated with reduced risk of mortality.

Current UK guidelines suggest that all adults should engage in 150 minutes of moderate or 75 minutes of vigorous physical activity per week, and public health strategies currently target everyone who is inactive to increase their physical activity level.

However the researchers, from the Institutes of Cardiovascular and Medical Sciences and Health and Wellbeing, suggest that a more targeted campaign at those who are unfit or have low grip strength could increase the clinical, and potentially cost, effectiveness of interventions.

Dr Jason Gill, from the Institute of Cardiovascular and Medical Sciences, said:

''We wanted to determine whether somebody's level of fitness or grip strength influenced the effect of physical activity on risk of mortality and cardiovascular disease.

''Our data showed that the benefits of being physically active were far greater in those with low levels of fitness or grip strength. Those with high fitness or strength were at low risk whether or not they had a high level of physical activity.''

It is well established that physical activity reduces risk of mortality and a number of diseases including heart disease.

However, this research suggests that there is a strong genetic component at play, which allows for people who are naturally fit or strong to gain some of the benefits of low risk of mortality and low risk of heart disease irrespective of whether they engage in physical exercise or not.

Dr Carlos Celis-Morales said:

''Our findings suggest that targeting on the basis of strength, and possibly fitness, could greatly improve our ability to identify those individuals who could benefit most from increased physical activity, thereby increasing the clinical and cost-effectiveness of physical activity interventions.

''Grip strength – the force applied by the hand to pull on or suspend from objects – is easy to measure and can be done quickly in healthcare and community settings, so this screening has potential for implementation.''

The authors add that it is possible that those with low fitness or strength may enjoy physical activity less than those who are naturally fit and strong, so it may be important to develop strategies to help support their engagement in physical activity.

The paper – The association between physical activity and risk of mortality is modulated by grip strength and cardiorespiratory fitness: evidence from 498,135 UK-Biobank participants' was published in *European Heart Journal*. The UK Biobank is supported by the Wellcome Trust, Medical Research Council, Department of Health, The Scottish government and the Northwest Regional Development Agency. The study was also had funding from the Welsh Assembly Government and the British Heart Foundation.

Source:
The University of Glasgow

An average 1 in 3 people across Great Britain have at least one long-term condition. Caring for them accounts for around 50% of GP appointments and approximately 70% of the health and social care budget across the country.

As the third largest health profession in the UK, the skills and expertise of pharmacists must be maximised within the multidisciplinary team to provide the best care for patients. Without changing the model of care, the NHS risks being unable to meet the unprecedented increase in demand for its services.

These new opportunities in clinical practice will enable pharmacists in all sectors to develop new roles.

The Royal Pharmaceutical Society (RPS) has published policy documents that focus on how the role of the pharmacist can be enhanced to prevent, identify, treat and support people with long-term conditions, as part of a multidisciplinary approach.

The RPS is making four key calls to action:

1. Pharmacists providing direct patient care should have the opportunity to train to become a prescriber, fully utilising those skills as part of the multidisciplinary approach to managing and supporting people with long-term conditions. To enable this change we are asking for the law to change to allow practising prescribing pharmacists to mentor pharmacists who want to become prescribers.
2. The patient journey will be made easier by enabling pharmacists to directly refer to appropriate health and social care professionals, improving patient access to care and reducing the number of unnecessary appointments.
3. Patients will benefit from further integration of pharmacists into their multidisciplinary team, ensuring support at every stage of their journey, from prevention through to treatment and management of their long-term condition(s).
4. All pharmacists directly involved in patient care should have full read-and-write access to the patient health record, with patient consent, in the interest of high-quality, safe and effective patient care.

The RPS launched the campaign in Wales. A separate parliamentary event took place in November at the House of Commons to mark the launch in England, with the launch in Scotland taking place in December.

Commenting on the launch, Suzanne Scott-Thomas, chair of RPS Wales, said:

''I am absolutely delighted with the level of support we have received for this initiative in Wales from within all sectors of the pharmacy profession as well as from other royal colleges and patient groups, including the Royal College of General Practitioners in Wales and Macmillan Cancer Care. The challenge of meeting the demands of long-term conditions has brought together a coalition of support to move this agenda forward…''

Sandra Gidley, chair of RPS England, said:

''Community pharmacists in England have had a tough year, with uncertainty replaced by a new reality of reduced funding through the national contractual framework. With this campaign we want to change the terms of the debate about community pharmacy in England. The new role for community pharmacists, supporting people with long term conditions within the heart of the NHS, needs buy-in from those across government and the NHS as well as those who own and work in pharmacies…''

John McAnaw, chair of RPS Scotland, said:

''This campaign gives us a great opportunity to further promote the role of the pharmacist around long-term conditions, and clearly outlines what is needed to allow further 'added value' in the delivery of frontline care. Our community pharmacies and pharmacists should have a greater role and profile in the delivery of care to people with long-term conditions, and I fully support the recommendations being made. With an increasing number of people now living with a long-term condition in Scotland, we already know that pharmacist's expertise in the use of medicines and in supporting self-management strategies can help people achieve the right outcomes from treatment.''

Source:
The Royal Pharmaceutical Society

Addenbrooke's education evening

In September an education evening for people with psoriatic arthritis and psoriasis and their relatives and carers was held in the Clifford Allbutt Lecture Theatre at Addenbrooke's Hospital in Cambridge. The event was a collaboration between PAPAA and the psoriatic arthritis clinic staff.

Consultant rheumatologist Dr Gavin Clunie set up the psoriatic arthritis clinic last year and handed the lead to Dr Deepak Jadon in February, following his move from the Royal National Hospital for Rheumatic Diseases in Bath. The psoriatic arthritis clinic is held every Tuesday morning and is supported by two of his very enthusiastic and learned colleagues, Dr Carmel Stober and Sister Dominique Raut-Roy.

During the two-hour evening meeting there were a number of talks, with the audience given the opportunity to ask questions

Dr Jadon presented an informative talk about what to expect as a patient with psoriatic arthritis, with emphasis on the epidemiology, pathogenesis, symptoms and signs of psoriatic arthritis. The talk gave a comprehensive overview of the condition and was well received.

Dr Jadon was followed by registrar Dr Carmel Stober, who spoke about testing for psoriatic arthritis, including what the tests are for, what they tell doctors and how they helped to understand how the condition has progressed. Dr Sober also gave an overview of the imaging that might be used when diagnosing and reviewing someone with psoriatic arthritis.

Next to speak was Sister Dominique Raut-Roy, who talked about the holistic approach in managing psoriatic arthritis with the purpose of sharing ideas regarding the understanding and the management of psoriatic arthritis. The presentation included the issues which are most important to her patients, such as nutrition, pain, fatigue, psychological impact, relationships, family life, flares and intimacy. The emphasis is to treat every person as an individual given his or her different circumstances.

In the final clinical talk Dr Gavin Clunie presented the management of psoriatic arthritis, both pharmacological and non-pharmacological, with the view that when you go and see your doctor they will be thinking really quite widely about how they can help you with your condition, and how you can help yourself. The mechanism of fatigue, Dr Clunie also considers, is a key to the understanding of the condition.

Event speakers: Dr Deepak Jadon, Sister Dominique Raut-Roy, Dr Carmel Stober, Mr David Chandler, and Dr Gavin Clunie

To end the evening David Chandler from PAPAA gave a presentation about the charity, its origins and current work. Mr Chandler, emphasised that PAPAA was a patient-driven organisation and was there to meet the needs of people with psoriasis and psoriatic arthritis; he encouraged people to not only engage with the charity, but to learn about the conditions and to be an active part of the management process when making decisions about treatment and care. This echoed much of what was said by the clinical team about an holistic and partnership approach.

Feedback received from those who attended overwhelmingly acknowledges it was a successful and useful event. Based on the positive feedback a second evening is being planned for 2017.
To find out more contact PAPAA (details on page 2) or visit
www.papaa.org/get-involved/events

Well I've had psoriasis for approximately four years now. It started off as a small area on my scalp and stayed there for a year or so' I'd first thought it was dandruff. Over the years it's spread over my back, face, arms, chest, legs and groin. To begin with it was just plaque, but over the past six months I've gained guttate as well.

It's affected my confidence badly, to the stage I'm now also being treated for depression and anxiety. It's affected my work life in that my employers regularly hold meetings with me and move me around my workplace.

I've always kept as positive an attitude as possible and tried to explain psoriasis to others who would ask. Recently while out shopping a young girl asked me about my arms. As I began to explain her mother dragged her away, screaming about how she shouldn't talk to dirty contagious people who don't wash.

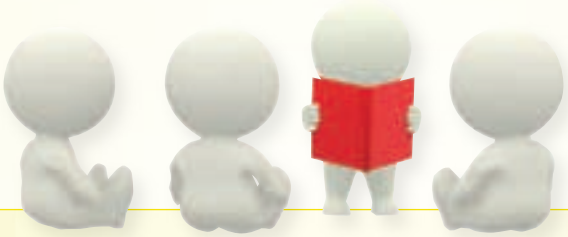
There have been few benefits from psoriasis to be honest. The main benefit I have noticed however is the overwhelming support I have received from my family and friends over it. Not once have they turned their backs on me.

I know it is hard to stay positive with this, but I strongly believe that we're only given the challenges that we are capable of enduring and overcoming.

Stay strong.
27-year-old male living in Northern Ireland

I have very little psoriasis, just on my scalp after the birth of each of my babies. After the birth of my fourth child in 2004, I started to develop aches and pains, but put this down to having four young children and working as a nurse. Then, in 2008, my index and middle finger began to swell and the toes on both feet.

I was referred to a hospital consultant with an interest in rheumatoid conditions, commenced on methotrexate. In 2014 having progressively got worse, neck stiffness, pain and swelling in both knees, which limited my ability to work



and made me very frustrated. Methotrexate by this stage was 20mg per week and made me so sick I could not function properly from Friday to Tuesday.

I asked for a second opinion and was referred to a rheumatologist - finally someone who understood! Before I left the consultation, I had multiple joint injections and drainage, an injection and addition of sulfasalazine to my treatment. Over the next 2 years, I had repeated joint injections as well as referral to physiotherapy and podiatry.

This year (2016), I was assessed and commenced anti-TNF treatment with monthly injections. This has made a massive improvement in my mobility and wellbeing. Not a cure, the symptoms can still bite!

To a stranger, I look well enough for a 45-year-old, and that can make life difficult. Even with the treatment I take, I am still in daily pain and stiffness, but have learned to get on with life as best I can.

45-year-old female living in Northern Ireland

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

Writings on the wall

On one of our recent Facebook postings we asked followers to tell us how they felt when they were first diagnosed with psoriasis and or psoriatic arthritis, with the following questions:

- **What did you think about the diagnosis?**
- **How long did it take to get a diagnosis?**
- **How did you cope with being diagnosed?**
- **What did you do to overcome the diagnosis?**

Here are some of the replies:

"I've had psoriasis since I was 12 and I had a poor body image because of how bad it was... hated psoriasis and how it made me feel inside. Was not actually treated by a dermatologist until 2009. UVB light worked wonders for my skin. Then the pains I have always had since my early 20s got worse, mostly tendon pain, and I was able to take it in my stride when I was diagnosed with psoriatic arthropathy. I am luckily in remission on methotrexate now. It's always been my psoriasis that has hurt me emotionally, I've had a lot of pain for years so it's just nice to have a name and treatment for it." **Posted by LH**

"I was relieved. Relieved finally to know what was wrong with me and why my feet blew up like balloons and I had to walk with crutches overnight. Relieved to have three doctors who collaborated to design my treatment. I did not think about the future. I thought only about NOW and getting relief NOW. And that I finally had an explanation for family, friends, and co-workers. I was grateful that the psoriasis was minimal for me despite 4 brothers and a father with it. The skin cleared up quickly and methotrexate and anti-TNF gave me back my mobility. Worries now? For my children and the hereditary factor. For my retirement (I'm 62 and diagnosed 15 years ago) and ability to afford the medications and treatment. Fear of retiring for that reason but fear of retaining my career both physically and cognitively. PsA has given me an appreciation for life. That's one positive." **Posted by SFE**

"I had psoriasis first, 30 years then GP sent me to a rheumatologist for diagnosis of joint pains and swollen feet. After tests, rheumatologist said "not as bad as rheumatoid arthritis". I was under him for three years and tried different medication. None agreed with me (I do have an intolerance to all medication). So it was goodbye. That was about five years ago. So I am having no treatment and don't know what the future holds." **Posted by AW**

"I did not know what to think. Did not know what to expect but now I certainly know I am in so much pain I wish it would all go away. The worst thing is I have tried so many different treatments I don't know what to do any more, I am fed up being a guinea pig." **Posted by GS**

"Fibromyalgia triggered in January 1987 but only diagnosed in 1997, and psoriatic arthritis about 7 years ago. Initial reaction was 'oh well, another diagnosis to deal with'. Very little psoriasis but major arthritis. Have been a guinea pig for: you name it, I've tried it. Last 12 months prescribed medication has not been able to keep pain down, so now on 7-day morphine patches twice a month. 61 and housebound. Rollercoaster of 'acceptance and fed up'. Best part for us all is a definite diagnosis to inform family and friends." **Posted by LTVD**

"It didn't sink in for a while to be honest, then after the initial shock I then did lots of research and tried to not read too much of the negative things but focus on the positives. It took a couple of years to get the final diagnosis. I'm now on my third type of medication and it is working for me and has made a big difference, although I now notice that I'm flaring more and having to up my pain medication, so I think it's time to up my medication. Until the specialist told me, I had never heard of it. I have had psoriasis since I was 13 but to be honest I never really understood what that was either. I still can't actually believe I have psoriatic arthritis." **Posted by NAM**

In another posting we were asked if we could post the following question anonymously:

"I had severe guttate psoriasis outbreaks from the age of 17 to 29... once every couple of years and always requiring outpatient treatment.

I knew each time it happened that would be me feeling terrible for the next year. It always occurred after a strep infection in my throat. Doc decided to remove my tonsils to see if it would help and I've been clear ever since (6 years now). I am wondering if anyone else has experienced similar? I wanted to let others know in case that kind of treatment might help them." **Posted by Anon**

We received these responses:

"I only started getting guttate psoriasis in my 20s but had my tonsils out at 11 years old. I still get strep throat infections even without my tonsils, just not as often." **Posted by KB**

"They were going to take mine out decades ago, but then medical thinking changed and they didn't. A few years later, several strep throat infectious later. Guttate psoriasis....my son was the same. They didn't take his out and he is covered." **Posted by RL**

"It is definitely one of my triggers but by no means the only one. Never discussed the possibility of tonsil removal as a potential help." **Posted by AB**

"I have had a bad flare of arthritis and pustular psoriasis when I have had strep. They seem to go together." **Posted by JWC**

"My psoriasis came on after I had my tonsils out!" **Posted by AL**

"Yes, mine too." **Posted by MC**

"I've suffered the same ... still got my tonsils though." **Posted by AJ**

"Complete cure for my psoriasis." **Posted by VM**

"I had never heard of psoriatic arthritis until diagnosed. I had psoriasis first and knew what that was, then very poorly with psoriatic arthritis. Quite upset at the time. Ten years on still fed up." **Posted by YD** *Please note post slightly edited to remove identifiers.*

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

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

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

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

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

Follow us on Facebook

Marketplace

PAPAA is a principal source of information on psoriasis and psoriatic arthritis and provides a FREE comprehensive selection of information on all aspects of both conditions.

Most of our material can be downloaded FREE from our website, but for those who do not have access or cannot print material, we can supply copies of the most popular information in printed format.

We are always keen to expand the information we provide, so if you cannot find what you are looking for, or if there are gaps which you feel need to be covered, please let us know, your feedback is vital to continue to build the resources you need.

We also have a selection of images on the website, but please remember that not everyone will develop the conditions in the same way and these images are illustrative and not an inevitable consequence. Most people have mild disease, which is managed successfully.

The popular starting information on the website is listed below:

- Just diagnosed
- Self-help
- About psoriatic arthritis
- About psoriasis
- Treatment overview
- Treatments - psoriasis
- Treatments - psoriatic arthritis
- Downloads
- A-Z encyclopaedia
- Image gallery

If you prefer we can send you a FREE information pack, which contains a list of the material on the website and describes how you can obtain copies.

To get a FREE information pack please contact us via the routes listed on page 2.

Visit the PAPAA shop

www.psoriasis-shop.org

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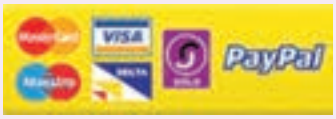
- Purchase from a selection of books
- Training programmes.



papaa

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.