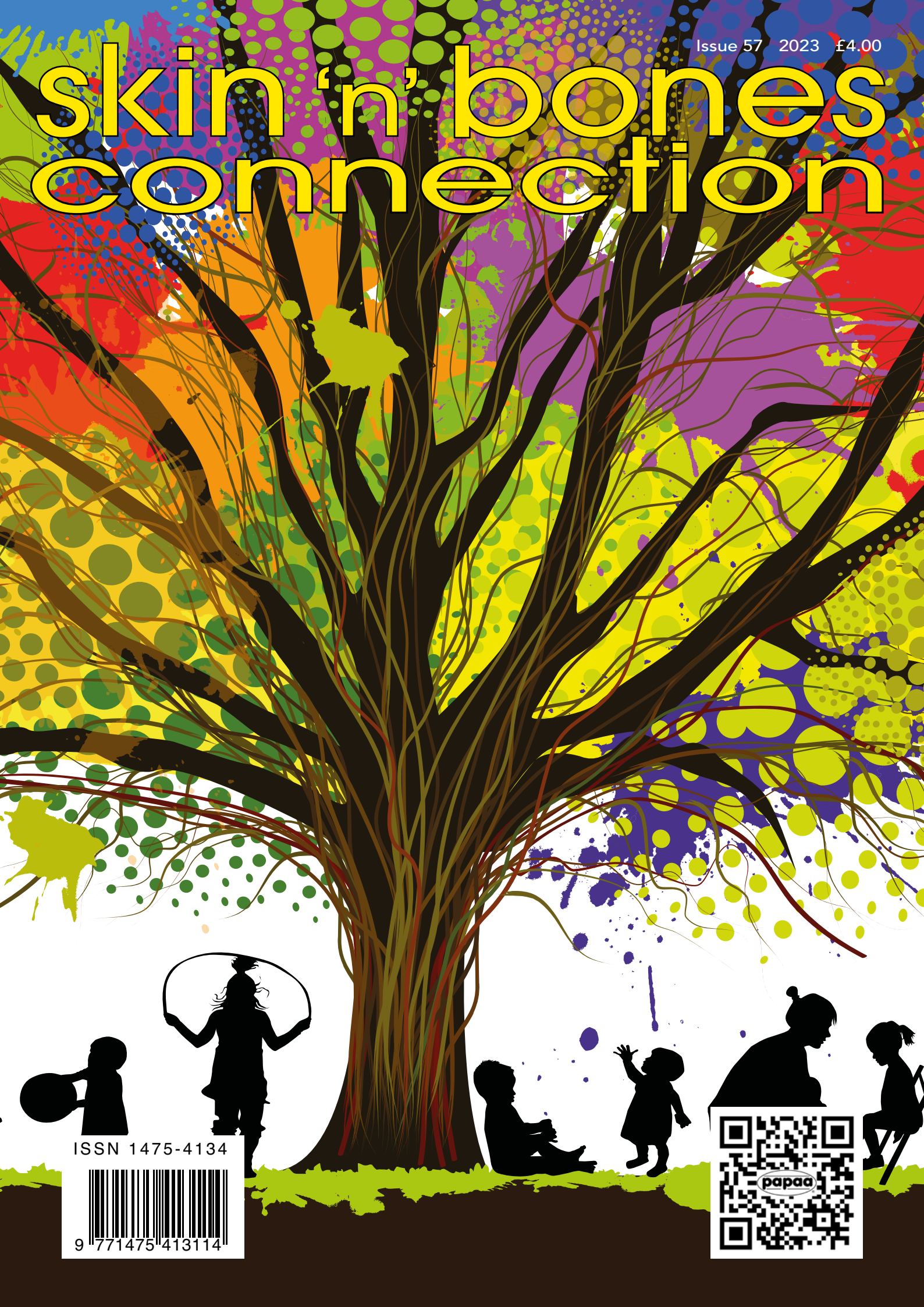


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Join the conversations

If you have a social media presence, then why not follow us and join the conversation to see what others have to say?

The following are the links to our pages:

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Pinterest: www.pinterest.co.uk/psoriasisuk

Instagram: www.instagram.com/the_papaa_eye

LinkedIn: www.linkedin.com/company/papaa/



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Dear Reader

In this issue we look at the future, while considering what the past can tell us. Being aware of previous generations, particularly to aid the diagnosis of hereditary conditions such as psoriasis, could offer useful insights (see page 3).

In an article starting on page 4 about assistive technology, we look at how, over time, making and adapting how and where people live is providing a more accessible world.

Although artificial intelligence (AI) is beginning to be discussed more in managing health decisions, we are perhaps still reliant on more traditional routes. Yet these have been difficult to access. Read more about changes to access on pages 6 and 7.

Of course, with all issues relating to our own health, safety is often a prime concern. On the centre pages we look at the safety evidence regarding tattoos and psoriatic skin.

Later, in the Pso Pscience section (starting on page 15), Dr David Ashton, PAPAA's senior medical advisor, explores some recently published studies that include the impact of relationship breakdown on health, the benefits of the Dead Sea and whether coffee is beneficial or not to people with psoriasis.

Managing editor

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.

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Disclaimer

The contents of the journal are aimed at providing information that may be of interest to people with psoriasis and/or psoriatic arthritis or those who have a specialist interest, whether in a personal or professional capacity. Some articles which will be included are of general interest and may or may not relate directly to either psoriasis or psoriatic arthritis. This material may include aspects related to health, services or products that are available.

We believe that at the time of printing all information is correct and cannot be held responsible for any inaccuracies that may occur, nor do we endorse any products that may appear in this journal.

All opinions are of the contributors and not necessarily those of the Psoriasis and Psoriatic Arthritis Alliance.

Always consult your own doctor or medical healthcare provider.

PAPAA is an independently funded UK patient-centred charity that supports both patients and professionals by providing material that can be trusted (evidence based), which has been approved and contains no bias or agendas

Main activities revolve around the themes of Care, Cause and Cure, where we provide extensive information, provide education and support research via a small grants scheme. Collaborative work is also part of the charity's activities, we are open to approaches to work together as a partner organisation or as a supportive promotor, to raise awareness of areas of activity, which are beneficial to people affected by psoriasis, psoriatic arthritis and associated co-morbid conditions, including other auto-immune mediated diseases.

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COVER PHOTO:

Childhood a colourful tree

By Ihnatovich Maryia

© www.shutterstock.com

When a child becomes ill, with any condition, it can be distressing not only for the child, but for the parents, siblings, relatives and friends. It is, after all, natural for a parent to be concerned and even worried about the health of their children. Even when their child is an adult, that concern and worry continues, particularly when they have a chronic condition.

So, what are the chances of a child developing either psoriasis or psoriatic arthritis? The heredity factor seems to play a part. About one third of people with psoriasis are able to identify a relative, living or dead, with psoriasis. It is estimated that if one parent has psoriasis, there is a 15% chance that a child will develop the condition. If both parents have psoriasis, this increases to about 75%. Interestingly, if a child develops psoriasis and neither parent is affected, there is a 20% chance that a brother or sister will also get psoriasis. This is because the condition is known to skip generations but somewhere there will be a familial link to a relative with psoriasis via either or both parents.

What triggers psoriasis in children?

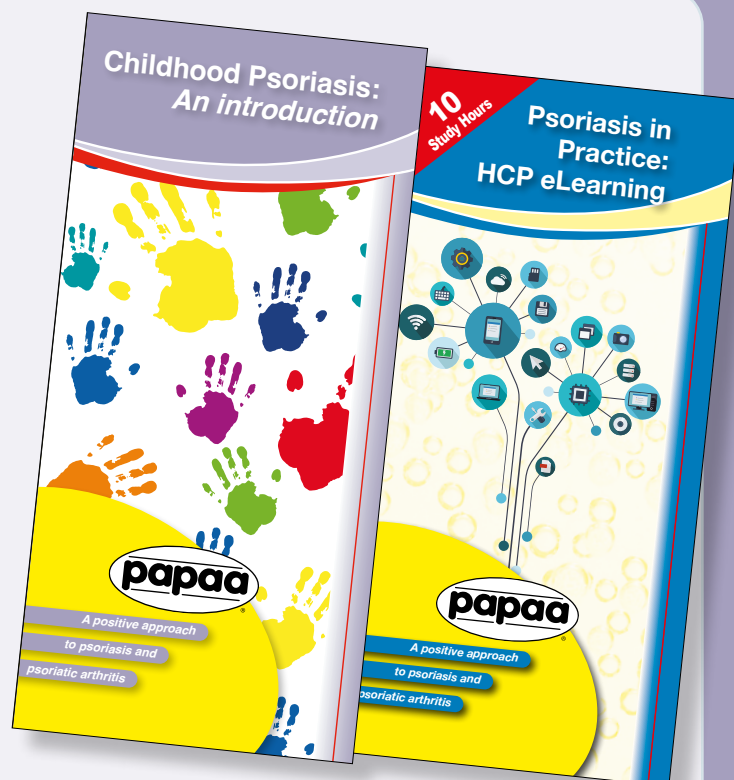
Symptoms only develop if they are triggered by certain events; most frequently in children and teenagers, symptoms follow a throat infection, due to streptococcal bacteria. This type of psoriasis is known as guttate psoriasis or raindrop psoriasis, so named because it manifests itself over the body in the form of scaly patches with a droplet-like shape. Numerous small, red, scaly patches quickly develop over a wide area of skin, although the palms and the soles are usually not affected. Some people will go on in later life to develop chronic plaque psoriasis.

What does psoriasis in babies look like?

Babies can develop psoriasis in the nappy area, appearing as a bright red, weeping rash or more typical psoriasis plaques. A child who has nappy area psoriasis as a baby does not seem to have a higher risk of developing other forms of psoriasis in later life.

What if a child develops a rash?

Any rashes on a child should be checked out by a doctor or healthcare provider, to rule out other conditions. If a child develops a rash, the doctor should be informed that there is a family history of psoriasis and/or psoriatic arthritis. This is important because, during initial diagnosis, psoriasis can otherwise be mistaken for another skin condition such as eczema.



What are the treatments for psoriasis in children?

Generally, those used in children are the same as for adult psoriasis, although there may be dosage differences and some products might not have a licence for use in children.

Raising awareness

Although there is a good understanding of psoriasis among healthcare professionals, it is not always considered as a possible diagnosis in young children. Raising general awareness in the wider population requires walking a fine line between causing unnecessary worry and providing insightful advice.

PAPAA has recently started a new childhood psoriasis campaign to support parents and raise the level of knowledge of healthcare providers in caring for children with the condition. Two initial pieces of activity have been developed; a new educational booklet aimed at parents, called *Childhood Psoriasis: An introduction*, and a training module for healthcare professionals in version 9 of our accredited *Psoriasis in Practice* online course. The aim is to develop further work to raise awareness that provides positive support and increases knowledge.

More information:
www.papaa.org/children

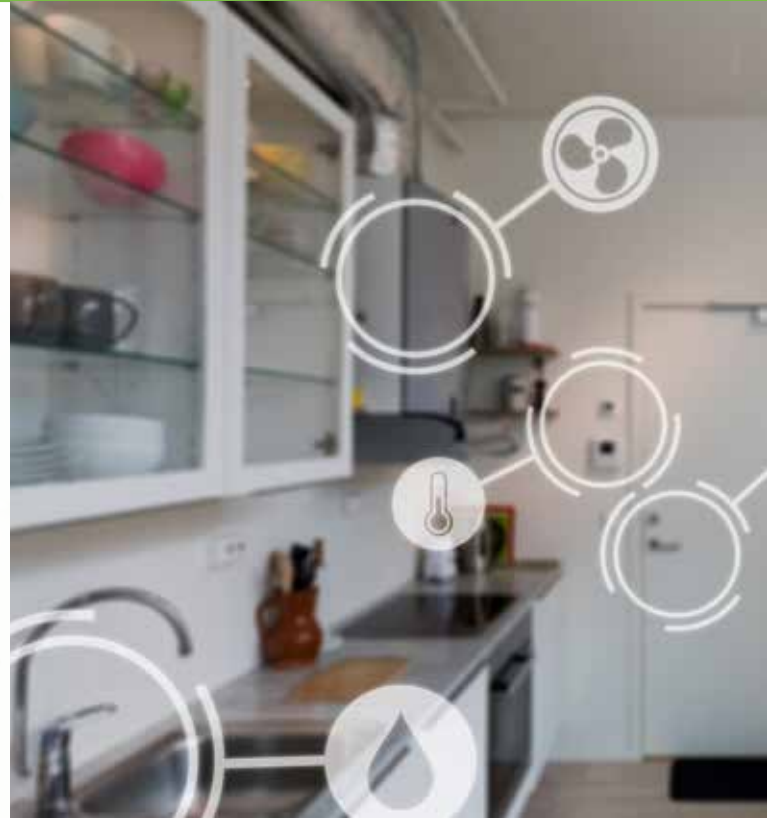
The rise and adoption of assistive technology

In modern society, the need for home, work and leisure environments to be accessible and inclusive are imperative to a functioning lifestyle. The inclusion of wheelchair accessible entrances, sensory assistance and products to help make life easier for those with a physical or psychological disability are common within healthcare. These products are designed to help the lives of those who live with visible and invisible conditions that impact their manual dexterity and movements, such as arthritis. In a fast-paced, demanding world, the prospect of completing everyday tasks, such as pouring from a kettle, doing up buttons on clothes, taking medication and turning taps, can feel daunting and frustrating, especially with a changing climate that impacts joint inflammation. These tasks can also be time-consuming for many with arthritis. Products that help with these everyday activities, and reduce physical toll and stress, can be life-changing.

Examples include button pulls, blister-pack poppers and easy-pour kettles. These gadgets are known as 'assistive technology', which is defined as "products or systems that support and assist individuals with disabilities, restricted mobility or other impairments to perform functions that might otherwise be difficult or impossible."¹ It is important to understand that not all products, while advertised as a medical device, are actually medically certified or will necessarily improve the quality of life of those living with joint inflammatory conditions. Whether they help or hinder will depend upon each individual's unique needs, lifestyle, financial limitations and living environment.

The advancement of technology and the rise of inclusive working and living spaces have improved throughout the 21st century, but the rise of assistive products has been slow. The Science Museum houses many examples of orthopaedic items created through the years, notably arthritis aids invented in the 1980s, such as a teapot stand made of plywood which makes it possible to pour tea without strain on joints.² Other examples include thick-handled cutlery and a tap turner. The designs and styles of assistive technology have changed over the years, but the theory behind them stays the same.

More recently, the University of Stirling, in collaboration with ceramics manufacturer Wade, designed a two-handled teapot to help pour those dangerously hot contents without spilling. This teapot is available to buy at Healthcare Pro, which



offers all sorts of assistive products. The Dignity by Wade ceramic collection is designed with such conditions in mind as arthritis, stroke, Parkinson's disease, cerebral palsy, multiple sclerosis, dementia and Alzheimer's disease.³

The collection is scientifically informed by research carried out by Stirling University's Dementia Services Development Centre to develop products that are easy to use and encourage independent eating and drinking.⁴ Other collections produced by Wade include Dignity Deco and Barchester, featuring brightly coloured adapted cups and bowls that stand out on the shelves, specifically for those living with dementia.

Thankfully, there are organisations which provide support and advice in choosing the appropriate assistive technology. Living Made Easy provides a range of products and information to help people understand the specific purposes of different items and where to buy them.⁵ AskSARA is an online tool offering advice, support and living aids to help make daily life manageable.⁶ This is a step towards inclusivity where manufacturers work in partnership with healthcare professionals. This type of collaboration is important in creating an environment where individuals can feel independent, and have the equipment they need to manage their condition and the impact it may have on their day-to-day activities. Stylish designs overturn the idea that functional living equipment



must be clinical in design.

Assistive technology is an important factor in everyday life and in the workplace, but this was not always the case. The way mobility and physical disabilities are viewed has changed throughout history. During the nineteenth century, the Victorians believed that disability was not a part of society and attempted to blend differences and hide them from everyday view. For example, prosthetic limbs were created to act and take the appearance of real limbs and are not the mechanical and sleek design that they are today. It was not until 1945, following the Second World War, that the way society and the government viewed disability began to change. After 1945, with 300,000 more disabled individuals in the UK, the need for improved mobility and access was becoming a topic of concern, especially after urbanisation in towns and cities.⁷ Public spaces were inaccessible and could not cope with the needs of the increased disabled population. To address this growing need for accessibility, in 1956 architect Selwyn Goldsmith, who became disabled after suffering polio, decided to dedicate his career to tackling 'architectural disability' and challenge 'institutional discrimination'.⁷ A survey reported that public toilets were one of the most challenging and inaccessible spaces for disabled people. Goldsmith's work revolutionised how architects approached public spaces.

In conclusion, the rise of assistive technology and successive governments' efforts to increase the services available is an important step towards inclusivity. The threshold fear of entering buildings and public spaces is one that many people face with physical, psychological, visible and invisible disabilities. However, new digital technology and artificial intelligence (AI) can help develop assistive products that are stylish, functional and inclusive, in the home as well as in public spaces. The continual drive to create inclusive spaces and encourage society to recognise that not all disabilities are visible can help many feel comfortable and reduce the stress when partaking in work, leisure and everyday activities.

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Source:

Amy Chandler BA, MA.

GP practices are being encouraged to join a new national online service making registering patients quicker and easier.

More than 900 GP practices – around one in seven nationally (14%) – have already enrolled for the digital register with a GP surgery service, which is managed by NHS England. Over 240,000 online patient registrations have been completed since its launch.

The service, which enables patients or carers to go online to find and register with a local GP practice, is now available in the NHS App, simplifying the process.

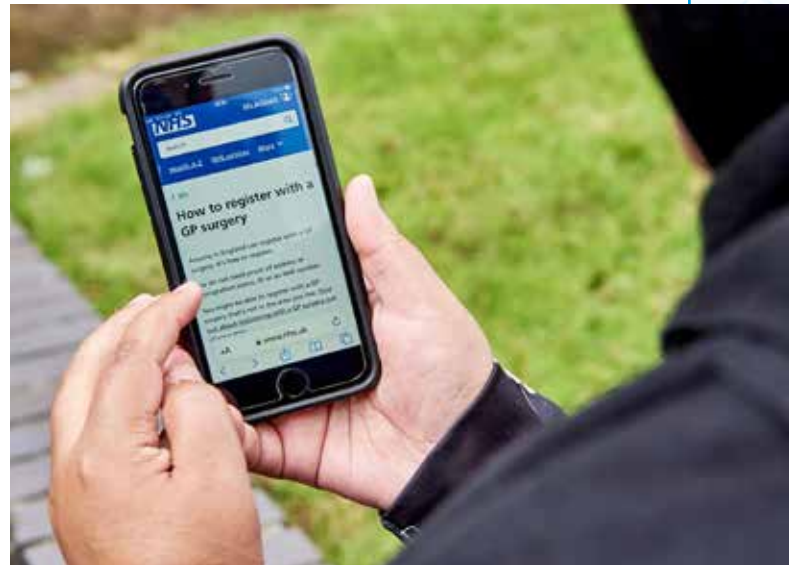
GP practices process around 6 million registrations a year, with many still using paper forms, so patients often have to visit surgeries to collect paperwork.

The new online service has been shown to save GP practice staff up to 15 minutes per registration by helping to reduce paperwork and admin time. The service, available to all practices, has been rigorously tested with users and a wide variety of patient groups, including charities who support homeless people and asylum seekers.

Patients can access the service using individual practice websites and the NHS website's Find a GP service, which is also available through the NHS App. Registration is quick and easy for patients, with the service automatically checking they live in the catchment area for their new practice.

Once registered, a patient's information is automatically emailed to GP practices in a structured format aligned to their IT systems, helping reduce the time it takes staff to process registrations. The service is fully integrated with NHS login, which enables people to use one login to access several health and care services, verifying their identity. It also matches patients to their NHS numbers, with a 90% first-time match rate, further cutting admin for practices.

The service is fully compatible with translator services, improving accessibility for non-native-



language patients and a new-look paper form is still available for anyone that needs it.

Stephen Koch, NHS England's executive director of platforms, said: "This service reduces the administrative burden for general practice as well as making GP registration even more accessible to the public, offering patients more choice, convenience and consistency.

"We're pleased to see a growing number of GP practices are coming on board, helping them save time and money. By recently integrating the service with the NHS App, we hope even more GP practices will take advantage of this new digital tool."

Dr Shanker Vijay, digital first clinical lead for London and a practising GP, is already using the service and also assists other practices to introduce it. He said: "We live in a 'one-click' culture and we recognise that many busy people want online solutions.

"Vulnerable patients and those with physical access needs don't need to visit the GP surgery to register, and people can access the service at any time, including outside of working hours to fit around their other responsibilities."

There are also plans to make the service compatible with a number of Robotic Process Automation (RPA) solutions, which use bots to enable registration information to be automatically added into GP clinical systems at the touch of a button, as an optional extra. Full clinical system integration is also planned for next year.



For more information:
<https://digital.nhs.uk/services/register-with-a-gp-surgery-service>



What is a Pharmacy First service? The term Pharmacy First means slightly different things depending on where you live.

In Scotland, the NHS Pharmacy First service launched in July 2020, offering anyone living in Scotland the opportunity to visit a pharmacist as their first port of call for minor illnesses, such as urinary tract infections, impetigo and acne.

Through the service, patients can access assessment, referral and free treatment for their ailment. Pharmacies receive a base payment of £1,250 each month and an activity payment from a funding pot of £785,000 if they provide a minimum of 100 consultations per month.

Commenting on the government's investment of £645 million into community pharmacies in England, the chair of the Royal Pharmaceutical Society in England, Thorrun Govind, said:

"We're pleased to see significant investment in this scheme for England, which is already successful in Scotland and Wales.

"Crucial to the success of Pharmacy First will be how it is implemented on the ground. The funding must flow to the frontline, who need to be supported to give patients the quality service they deserve.

"The plans announced are a real game-changer for patients as they will provide better access to healthcare, helping to reduce the strain on other parts of the NHS and provide patients with the care they need, when they need it. They provide further endorsement of the crucial role that pharmacies play in helping the public at the heart of primary care.

"We welcome the government's plans that provide additional investment into the sector and that seek to ensure everyone across the country has equal

ROYAL PHARMACEUTICAL SOCIETY

access to care from highly skilled pharmacists and their teams. These plans will help to reduce health inequalities, especially in deprived areas where pharmacies are at the heart of their communities and trusted by patients.

"Our Vision for Pharmacy Practice in England, developed with The King's Fund, showed how the accessibility of community pharmacy will be a key consideration in the future of patient care. It also highlighted the importance of a core consistent service across the country, so that the public can understand what care they can access no matter where they live.

"Providing treatment to help prevent common conditions from becoming worse and requiring more complex treatment later on is better for patients and also cost-effective. Patients can expect to receive trusted advice from pharmacists in their local pharmacy.

"Over 14,000 pharmacists, trainees and undergraduates have been upskilled through the RPS Community Pharmacy Consultation Service, training on exactly the kind of conditions that Pharmacy First will cover.

"We look forward to working with NHS England, community pharmacies and other pharmacy organisations on the development and rollout of this plan."

**Source:
RPS News**

Did you know that uveitis, a condition that affects the eyes, is more common in people with psoriasis and psoriatic arthritis? Uveitis often happens in people who have an autoimmune condition. This is where the immune system mistakenly attacks healthy tissue. The risk is higher if gene HLA B27 is present, which is common in spondylitis subgroups.

Uveitis means inflammation of the uvea. This can affect the iris (iritis), ciliary body (cyclitis) or the choroid (choroiditis). Symptoms depend on whether all or just part of the uvea is affected, but may include:

- dull, aching pain in the eye
- redness
- blurred or misty vision
- a muddy appearance to the coloured iris in the affected eye
- a pupil appearing smaller than on the other side and irregular in outline.

Symptoms can affect one or both eyes. Inflammation is thought to result from the immune system attacking the cells of the uvea. Treatment of uveitis is required urgently, to stop the inflamed iris from sticking to the lens behind. This would cause permanent damage to the eye and can also trigger glaucoma (a rise in fluid pressure in the eye due to blocked drainage channels). Uveitis often returns from time to time and it can occur whether arthritis currently active or not.



Note: Children with psoriatic arthritis should have regular screening tests for uveitis as they may not develop symptoms until their eyesight has been damaged and irreversible visual impairment takes place.



Treatment

Inflammation is damped down with eye drops containing corticosteroid drugs. In severe cases, you may also need to take steroid tablets by mouth to boost the effect of the drops.

Eye drops that relax the iris and ciliary body are also used. These make the pupil dilate and ensure that an inflamed iris does not stick to the eye lens (posterior synechia).

The inflammation is monitored by regular examination of the eye using a slit-lamp. If steroid eye drops are used for prolonged periods, the fluid pressure in the eye will also need to be checked regularly. This is because long-term use of steroid drops can cause a form of glaucoma.

If you are worried about your vision, contact your healthcare provider as soon as possible, particularly if you have persistent eye pain or an unusual change in your vision.

Useful contact

The Royal College of Ophthalmologists can provide a list of practising eye specialists:

www.rcophth.ac.uk

NHS UK:

www.nhs.uk/conditions/uveitis/causes/

Source:

PAPAA Knowledge bank

The European Alliance of Associations for Rheumatology (EULAR) has announced the launch of the EULAR Impact of rheumatic and musculoskeletal diseases (RMDs) Survey, an online questionnaire targeted directly at RMD patients.

The data collected through this survey will be an important resource for researchers, healthcare professionals, and patients alike, providing a comprehensive database of patient-reported outcomes describing their healthcare situation and how the illness affects their social and occupational lives.

By collecting and analysing data from a large number of patients with RMDs on a recurring basis, the survey will provide valuable insights into the burden of disease and help improve the overall care for people living with these conditions.

"EULAR is committed to improving the lives of people with rheumatic diseases," said Dr Anna Molto, chair of the EULAR Research sub-committee of epidemiology and public health, and lead of the project. "The launch of this survey is a significant step forward in our efforts to better understand how rheumatic diseases impact the lives of patients across Europe and to identify healthcare gaps and unmet needs.

"The information gathered through the questionnaire will be used to support research studies, clinical trials, and other research initiatives aimed at improving patient outcomes. It will also serve as a tool for monitoring disease trends and treatment patterns over time, which can help guide clinical practice, policy decisions and advocacy activities."

"The EULAR Impact of RMDs Survey is an important resource for the entire rheumatology community," said Professor Annamaria Iagnocco,

EULAR president. "By working together and sharing data, we can make significant progress in the fight against rheumatic diseases."



The project is designed to collect data directly from patients through an online survey. A baseline survey will capture information about the patient's general demographic and sociographic situation, as well as several standardised questions related to their RMD diagnosis and how it impacts their quality of life.

Recurring follow-up surveys on a bi-annual basis will allow for a longitudinal observation, as well as additional disease-specific sub-questionnaires as needed.

All information will be de-identified to protect patient privacy and comply with relevant data privacy regulations. EULAR encourages all patients to participate in the EULAR Impact of RMDs Survey by sharing relevant information and insights into their lives with an RMD. For more information on how to take part, please visit the website.

About EULAR:

EULAR is the European umbrella organisation representing scientific societies, health professional associations and organisations for people with rheumatic and musculoskeletal diseases (RMDs).

Learn more at:

www.eular.org/eular-impact-of-rmds-survey

Source:

EULAR June 2023



Nowadays, it seems that almost every TV celebrity and sports star parades some form of body art, especially tattoos. Among professional footballers, having at least one arm fully tattooed seems to be de rigueur. Historically, there was a strong element of class stigma associated with tattoos and some still think having a tattoo is confirmation of working-class status. Others, however, see it as an attractive form of self-adornment which transcends class divisions. But whether you are for or against, there is no doubt that attitudes towards tattooing in the UK have changed significantly over the last 50 years. Just 7% of people born in the 1950s are likely to have a tattoo compared with 42% of people born in the 80s and 90s.

Of course, tattooing has been around for a long time – a very long time. The oldest known human to have tattoos preserved upon his mummified skin is a Bronze-Age man from around 3300 BCE. He was found in 1991, in a glacier of the Ötztal Alps, near the border between Austria and Italy. “Ötzi the Iceman” has no fewer than 61 tattoos, which are in remarkably good condition given the circumstances – proving that tattoos can age well.

Some consider the birthplace of modern tattooing to be New York City, because it’s where the first professional tattoo artist, Martin Hildebrandt, established himself, tattooing Civil War soldiers for identification purposes. His protégé, Samuel F. O’Reilly, was also a key figure in tattooing history and is credited with inventing the electric tattooing machine, which came into use in the late 1880s.

Today, the United Kingdom is the most tattooed nation in the world, with an estimated 30% of 18-35-year-olds having at least one tattoo. According to a recent survey, Birmingham is the most tattooed city in the country, with close to half (48%) of the population having tattoos.¹

What are the risks of getting tattooed?

There are general risks of tattooing which are not specific to people with psoriasis. These include:

- skin infection – always a possibility from poor skin preparation and dirty instruments
- blood-borne infections from dirty needles – hepatitis B, C etc
- allergic reactions – tattoo dyes, especially, red, green, yellow, and blue, may cause itching and swelling of the skin



- scarring (known as keloid formation).

But the complication most relevant to people with psoriasis is the Koebner phenomenon.

Koebner phenomenon

People with psoriasis and some other skin diseases, like lichen planus and vitiligo, are most at risk for a skin reaction known as the Koebner phenomenon (also known as the isomorphic response). It was first described by the 19th century German dermatologist, Heinrich Koebner (1838-1904). With this condition, new skin lesions – similar to those of the diseased skin – appear on normal, healthy skin. This usually occurs following traumas such as scratches, cuts, abrasions, or burns, to the normal skin and – of course – tattooing. So, a tattoo in an area of skin not normally affected by psoriasis can develop psoriasis-like lesions.

In fact, the Koebner phenomenon can occur in any anatomical site, including the face. Even mild trauma to the skin, such as from very tight waistbands or heavy shoulder bags, can be enough to cause a Koebner response.

The cause of the phenomenon is not entirely clear, but recent evidence suggests that specialised tissue-resident memory (TRM) cells may be involved. These cells may cause the body to respond inappropriately to perceived threats – like scratches and tattoos – by releasing inflammatory molecules which are involved in the development of psoriasis.

Fortunately, in most cases the Koebner response – if it occurs – is relatively short-lived and easily treated.

What does the scientific evidence tell us?

In recent years – probably because of the rapid rise in the popularity of tattooing – scientists have started to pay much more attention to the potential risks (and benefits) of tattooing for those with psoriasis. What do they tell us? Three recent studies actually reveal quite a lot.

Study 1

In this 2016 study, researchers carried out an internet survey of 90 psoriatics to determine their attitudes towards tattoos, their motivations, and the incidence of complications.² 52% (48/90) had one tattoo or more and – unsurprisingly – they were younger than the non-tattooed individuals. Of the tattooed subjects, 13 (27.6%) experienced a Koebner reaction on their tattoos, though in only 4 cases did this occur within weeks of tattooing. In the remainder, it occurred anywhere from months to years after tattooing. Fewer than 7% reported a psoriasis flare-up on another part of the body after tattooing. It's also worth noting that 91.5% (43/47) did not discuss their wish to get a tattoo with their doctor, but 43.5% (20/46) alerted their tattooist to their psoriasis. Importantly, 82% stated that their tattoo(s) had a positive effect on their body image.



Study 2

In this large (2020) study, researchers from multiple locations in France aimed to evaluate the frequency of tattoo complications in people with psoriasis and determine whether the occurrence of complications was associated with psoriasis status and treatments received at the time of tattooing.³

A total of 2053 adults with psoriasis were included and classified as tattooed or non-tattooed.

Prevalence of complications associated with tattoos was then evaluated according to psoriasis onset and treatments. Data were collected through a series of questionnaires filled in by a dermatologist. Complications included itching, allergic reactions, infections, swelling, psoriasis flare and Koebner phenomenon.

Of the 2053 participants, 414 (20.2%) had a total of 894 tattoos. Among psoriatics without tattoos, 252 (15.4%) had wished to have a tattoo but never received one. Amongst these people, 111 (44.0%) did not have a tattoo either because of their psoriasis, the treatment for their psoriasis or due to negative advice from their doctor. Finally, 93 (5.7%) of the non-tattooed individuals planned to have a tattoo in the future.

Local complications, such as oedema, pruritus, allergy, and Koebner phenomenon, were reported in tattoos in 58 (6.6%) subjects, most frequently in those with psoriasis requiring treatment at the time of tattooing. Koebner phenomenon occurred in just 26 (3%) and tattooing caused psoriasis flare-up in 29 (3.2%) of cases, independently of the occurrence of Koebner phenomenon. No severe complications were reported. It's notable that the risk of complications, whilst low, was higher in those undergoing active treatment for psoriasis, especially with biological agents.

Study 3

In the third study (2022), this time from Poland, researchers conducted an anonymous, online questionnaire-based study in order to assess how much those with psoriasis know about tattooing and its potential complications.⁴ They enrolled 150 tattooed psoriatics between April and September 2020.

Of 150 respondents, 134 were female and 16 were male, with an age range of 16-62 years with a mean age of 32 years. Most respondents received their psoriasis diagnoses before getting tattooed (114/76%), whereas 36 (24%) were diagnosed afterwards. Interestingly, only 8% (12) had a dermatological consult before getting their tattoos, and only 18% of respondents reported that the tattoo artist had recommended a dermatological consult prior to tattooing. Investigators reported 101 (67.3%) of respondents were undergoing active treatment for psoriasis while being tattooed.

Overall, tattooing complications for people with psoriasis were mild and more prevalent during active disease or with systemic treatment. Only 13 (8.7%) of respondents had tattoo-associated cutaneous complications, with Koebner phenomenon most frequent (8/5.3%). In one of these cases, the tattoo was the first onset of psoriasis. Only two respondents (1.3%) reported a general flare-up of symptoms and just two reported an itchy rash at the site of the tattoo.

What can we say from the evidence?

All three studies have important information, not just for anyone with psoriasis who may be considering a tattoo, but for any healthcare professional or tattooist who may be asked to advise psoriatics about the associated risks. Below are the key points we can take from the three studies considered above.

- First, there were no serious complications observed in any of the studies and the risks associated with tattooing in people with psoriasis are consistently low.
- Whatever complications did occur were more common in those on active treatment for psoriasis at the time of tattooing.
- In Studies 2 and 3, the Koebner phenomenon occurred in just 3% and 5.3% of patients respectively. In Study 1, it was much higher at 27.6%, but the method of reporting in this study was unusual, and the truer figure is around 8.5% - which is more consistent with the other findings.
- Generalised flares were uncommon after tattooing and no one reported a worsening of psoriatic arthritis.
- Most subjects did not discuss having a tattoo with their doctor prior to having it done.
- There is no evidence that psoriasis improves as a result of tattooing.
- The vast majority of those with psoriasis said that having a tattoo had positive psychological benefits in terms of self-esteem and self-image.

Practicalities – what to do if you want a tattoo

On the basis of the scientific evidence, there is no reason why you shouldn't consider having a tattoo if you have psoriasis. Overall, you can be reassured that the risks are small, though not irrelevant.

So, here are three sensible precautions to take before going ahead.

1. First, if you are undergoing active treatment for psoriasis – especially with biologic drugs – it would be wise to discuss your intentions with your healthcare provider. As we have seen, those under active systemic treatment are more likely to experience complications, though even in this group, these are not severe.
2. Second, keep in mind the small, but not insignificant, risk (around 5-10%) of a Koebner response developing in the tattoo itself. This may occur early but may also occur many months or even years later. This may alter the appearance of the tattoo in unpredictable ways; it may fade, discolour, or even disappear entirely.
3. Third, make sure you choose a reputable tattooist and make sure she/he is fully aware of your skin condition before you decide to go ahead. Not all tattooists are willing to work on individuals with skin conditions, so be prepared for disappointment!

Dr David Ashton MD PhD

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Driver & Vehicle
Licensing
Agency

Getting behind the wheel is something many of us do on a daily basis. Whether it's to take your children to school, go to work or collect your weekly food shop, driving plays an important role in many people's lives. However, there are several health conditions that can have a significant impact on our ability to drive in a safe and secure manner.

If you suffer from a specific condition, it's always wise to check if you need to declare it to the Driver and Vehicle Licensing Agency (DVLA).

In fact, if you don't inform the DVLA of a medical condition that could affect your ability to drive, you could be fined up to £1,000.

More importantly, you could put yourself, as well as fellow motorists and road users, at serious risk of incident and injury. Should an accident happen because of your condition, you may even face prosecution.

With a register of nearly 200 health conditions that could hinder your driving skills, it's worth finding out if yours appears on the DVLA list. In the meantime, here are a few common medical conditions that may affect your driving, along with tips on how to stay safe in your vehicle.

The conditions include epilepsy, diabetes, heart conditions, stroke or a transient ischaemic attack (TIA) and arthritis.

If your arthritis is having an impact on your ability to drive, or it requires you to use special controls, you need to tell the DVLA. This is especially the case if the condition has lasted over three months.

While arthritis shouldn't prevent you from being in control of a vehicle, there are a few steps you can take to make your journey more comfortable.

For example, you may want to pad your steering wheel with some sort of cover, such as foam tape, add a neck support to the headrest or build in mirror extensions to provide you with a better, wider view of the traffic behind you.

On long journeys, make sure to stop and take regular breaks to stretch and loosen up. Remember also to adjust both the steering wheel and driving seat – keeping them at the right height and position will help prevent pain and discomfort in your joints.

Whatever your ailment, from epilepsy or diabetes to arthritis and heart problems, make sure to inform the DVLA to ensure you comply with regulations, ensuring that you, your passengers and any other road users are safe. With a few simple steps, you can sit in your driving seat with confidence and peace of mind.

Other issues that need to be considered when driving include prescription medicines; it's illegal in England, Scotland and Wales to drive with a legal drug in your body if it impairs your driving. It's also an offence to drive if you have more than the specified limits of certain drugs in your blood and you have not been prescribed them.

For more information:

www.gov.uk/health-conditions-and-driving

www.gov.uk/drug-driving-law

A new regulatory pathway has been set up to support safe patient access to innovative medical technologies. Set for launch later in 2023, the Innovative Devices Access Pathway (IDAP) will be operated by the Medicines and Healthcare products Regulatory Agency (MHRA), the National Institute for Health and Care Excellence (NICE), Health Technology Wales (HTW) and Scottish Health Technology Group (SHTG), including the devolved administrations.

Plans are advancing for a new regulatory pathway that facilitates the development of innovative technologies by providing innovators and manufacturers with a multi-partner support service, including targeted scientific advice that brings new products to patients sooner.

The ambition of this new programme is to bring innovative technologies and solutions to the forefront of the National Health Service (NHS), through a new, integrated support service for developers, that will include enhanced opportunities for engagement.

The aim is to help take uncertainty out of the route to access, bringing innovative technologies to patients that can transform health outcomes.

Innovators of medical technology (commercial or non-commercial, UK-based or international) that addresses clinical needs are being encouraged to register for further information ahead of a planned 2023 pilot launch. Initial interest is requested via email at IDAPEnquiries@mhra.gov.uk.

Once IDAP is up and running, its partners will use the lessons learned from the pilot to help develop the pathway, creating an end-to-end visible framework that supports innovators generate the evidence they need to achieve regulatory approval, health technology assessment decisions, and patient access in the NHS.

Dr Marc Bailey, MHRA chief science and innovation officer, said: "The new IDAP will demonstrate how the UK regulator, health technology assessment and the healthcare system are working together to deliver safe, effective, and earlier innovative medical products to patients, establishing the UK as a centre for medical innovation.

"We would welcome early interest from potential applicants, so we can keep them updated as this key partnership and pathway develop."

Mark Chapman, interim director of medical technology and digital evaluations at NICE, said: "We look forward to working with industry to continue the acceleration of our evaluations and with the MHRA to align our work for the benefit of patients."

Dr Susan Myles, director of health technology Wales, said: "Now, more than ever, innovative solutions are needed to address healthcare challenges. We look forward to working in partnership with organisations from across the UK to ensure that IDAP helps to accelerate the development and adoption of these technologies for the NHS."

About MHRA:

The Medicines and Healthcare products Regulatory Agency (MHRA) is responsible for regulating all medicines and medical devices in the UK by ensuring they work and are acceptably safe. All of its work is underpinned by robust and fact-based judgements to ensure that the benefits justify any risks. The MHRA is an executive agency of the Department of Health and Social Care.

MHRA news:

26 May 2023

In sickness and in health?

Previous studies have shown the adverse consequences of marital breakdown on health, but very few have investigated the impact of health on marital breakdown. What evidence is available suggests that chronic illness may be a significant factor in marital dissolution. One study of 2,701 marriages focused on four main diseases – cancer, heart disease, lung disease and stroke – and found that the advent of illness in the wife, was linked to a greater risk of divorce, but onset of illness in the husband was not.¹ Whilst there is ample evidence that psoriasis can cause relationship problems, often due to problems with self-esteem and intimacy, no studies until now have specifically investigated the possible impact of psoriasis on marital dissolution.



In this Italian study, researchers used a validated questionnaire – the Quality Marriage Index (QMI) – a 6-item measure of marital satisfaction.² Two groups of patients were recruited, 100 with moderate-to-severe plaque psoriasis and 101 healthy controls. Each patient enrolled in the study completed the QMI questionnaire. Analysis of the results showed that a significantly higher number of psoriatic patients were divorced than patients without psoriasis. Moreover – and unsurprisingly – patients with psoriasis had lower QMI scores than the healthy controls, suggesting lower marital satisfaction. The authors conclude that psoriasis may contribute to marital breakdown.

Comment

This is the first study to specifically investigate marital problems in patients with psoriasis. The results are hardly surprising and mirror what is already known about the effects of other chronic diseases on marital discord. The difficulty in qualitative studies of this kind is how one can be sure that the measure used (in this case QMI) actually measures what it claims to. Some may have serious doubts that a 6-item questionnaire could begin to capture what is most essential about any partnership. Nevertheless, this study is a timely reminder that psoriasis imposes a significant psychosocial burden on the lives of patients, including their personal relationships, to a degree comparable with other serious chronic conditions.

References

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Dead Sea spa holidays

The Dead Sea, the deepest and most saline lake on earth, has been known since biblical times for its therapeutic properties. Situated between Jordan, Israel, and the West Bank, it has a salt content of 34.8% (sea water is around 3.5%) and very high concentrations of minerals such as sodium, magnesium and potassium. Together with dry air and low-intensity UV light, these factors contribute to what is claimed to be an ideal climate for eczema and psoriasis sufferers and for those with various arthritic conditions. Unsurprisingly, the Dead Sea, the Sea of Galilee, and the hot springs of Ein Gedi on the Dead Sea's western shore, have become the location for a thriving health-tourism industry. Nowadays, specialised travel companies offer packages to a variety of health spa hotels and medical centres, providing what is sometimes referred to as Dead Sea climatotherapy (DSC).

It's well known that DSC produces rapid improvements – or complete remission – in patients with psoriasis and other skin conditions. But the question is whether these benefits are sustained. In this small study, Danish researchers sought to determine both the efficacy and the duration of benefit of DSC in 18 psoriatic patients who took part in a 4-week treatment programme in Ein Gedi in Israel, consisting of both sun exposure and sea bathing.¹ Measures of disease severity included the Psoriasis Area and Severity Index (PASI) and the 5-point Investigator's Global Assessment (IGA) Scale, a modified tool for evaluating plaque psoriasis severity in clinical trials.

Results showed that treatment had an immediate benefit, with patients experiencing an average 13-point reduction (88%) in PASI scores and 2.3 (76.7%) on the IGA Scale. Ten patients (55.6%) achieved complete clearance. At follow-up, the average time from treatment end to reappearance of visible skin symptoms was 93.8 days.

Comment

This is a very small study, but the results are entirely consistent with previous findings, which show that DSC is an effective treatment option for patients with psoriasis, improving both skin lesions and overall quality of life, with no adverse effects. Unfortunately, it also confirms that the observed benefits are short-lived; in this study the interval between end of treatment and recurrence of skin symptoms was 93.8 days (13.4 weeks). Other studies have shown similar remission durations. On the other hand, many will think a disease-free period of 3-months, or more is well worth the cost – especially if the treatment is part of a holiday!

Reference

1. Emmanuel T, Lybæk D, et al. Effect of Dead Sea Climatotherapy on Psoriasis; A Prospective Cohort Study. *Front Med (Lausanne)* 2020; 7:83

Maternal psoriasis and premature births

It is well known that women with certain inflammatory diseases, such as rheumatoid arthritis and inflammatory bowel disease, have an increased risk of giving birth to infants who are either small for gestational age (SGA) or preterm birth (PTB). However, few studies have examined this association in women with psoriasis, which is exactly what a very large Danish study set out to do.¹

Researchers used a nationwide database, collected between 2004 and 2017, containing information on 516,063 deliveries. From this, investigators identified 6282 (1.2%) with psoriasis who were then matched with 62,798 women without psoriasis (controls). PTB (premature) birth was defined as a gestation of <37 weeks and SGA, as a baby of birthweight < 10th percentile.

Results showed that the risk of SGA and PTB in women with psoriasis was similar to that in the matched controls.

Comment

This was a large and well-conducted study which clearly showed that maternal psoriasis did not increase the risk of giving birth to small-for-dates or premature infants. Whilst further studies are needed, these findings are obviously reassuring for women of childbearing age who also have psoriasis.

Reference

1. Bachdal Johansen C, Egeberg A et al. Association of maternal psoriasis and small for gestational age or preterm birth: a nationwide matched cohort study in 69 080 singleton infants. *Clin Exp Dermatol* 2022; 47:1115-1123

Another milestone in drug therapy

In September 2022, the US Food and Drugs Administration (FDA) gave its approval for an exciting addition to the therapeutic options for the treatment of psoriasis.¹ It has not yet been approved for use in the UK, but is currently being appraised by the National Institute for Health and Care Excellence (NICE), which is expected to publish its recommendations in March 2023.

Deucravacitinib (Sotyktu™) is a tyrosine kinase 2 (TYK2) inhibitor, developed for the treatment of adults with moderate-to-severe plaque psoriasis. Patients participating in clinical trials achieved the Psoriasis Area and Severity Index (PASI) 75, which means that after 16 weeks of treatment, they had at least 75% improvement in symptoms.

Normally, your immune system works to protect you from infections and illnesses. TYK2 is one of the molecules that plays a key role in signalling to the immune system and usually helps to create new skin cells only when they are needed. But in psoriasis, it seems that TYK2 becomes overactive, sending out too many signals, leading to an increase in inflammatory molecules called cytokines. Deucravacitinib selectively targets and inhibits the action of TYK2, thereby reducing the inflammatory response and improving the skin manifestations of psoriasis.

What is remarkable about deucravacitinib is that it appears to have the efficacy of biologic drugs – which have to be given by injection or IV infusion – in a once-a-day tablet form. Moreover, the drug appears safe and well tolerated.



Comment

This is another welcome milestone in the development of effective treatments for psoriasis, building on the growing understanding of what creates the inflammatory response in skin conditions like psoriasis and eczema. Since the advent of biological therapies, which have revolutionised the management of psoriasis, the hope was that something as effective could be given in a once-a-day tablet form. Deucravacitinib is the fulfilment of that hope and is very likely to become the new standard of care for moderate-severe plaque psoriasis in adults. Whilst not currently available in the UK, it is likely to become so in the very near future.

Reference

1. Hoy SM. Deucravacitinib: First Approval. *Drugs* 2022; 82:1671-1679

Immune surprise

The astonishing developments in drug therapies for psoriasis are only possible because scientists have painstakingly unravelled the forbiddingly complex mechanisms which underlie the inflammatory response in psoriasis and psoriatic arthritis. And sometimes basic research throws up real surprises!

Scientists at Trinity College Dublin recently made an important breakthrough in understanding how inflammation is regulated.¹

While our immune system serves a very important function protecting us from infection and injury, when immune responses become too aggressive this can lead to damaging inflammation, which is a clear hallmark of conditions such as rheumatoid arthritis and psoriasis. Inflammation is triggered when our bodies produce "alarm proteins" (called interleukins), which enhance our defences against infection by switching on different components of our immune system. Obviously, understanding how and when such alarm proteins are produced and how they activate our immune system has led to major breakthroughs in the treatment of many immune conditions, psoriasis included.

Now, the Trinity scientists have discovered that an alarm protein called Interleukin-37, which was previously believed to serve as an "off switch" for the immune system, actually does the opposite. In other words, instead of calming down the immune system, Interleukin-37 actually promotes the inflammatory response.

Comment

Fundamental research of this kind doesn't generally get much press or media coverage; news outlets are only interested in "breakthroughs" or, better still, cures. But modern treatments of the kind we have grown used to – nowhere more remarkable than in psoriasis – depend entirely upon the results of basic research such as this.

Reference

1. Sullivan GP, Davidovich P et al. Myeloid cell-derived proteases produce a proinflammatory form of IL-37 that signals via IL-36 receptor engagement. *Science Immunology*, 2022; 7 (78)



More coffee?

Coffee is one of the most consumed liquids, regardless of geographical region. According to the evidence, only water and tea are more frequently consumed. Importantly, coffee is a pharmacologically active fluid.

There are many biologically active substances in its composition, the most studied of which is caffeine. Among other properties, it has been shown to have anti-inflammatory effects, which may suggest that it could be of benefit in psoriasis. However, the evidence is somewhat contradictory. Some studies have shown that increasing coffee consumption is associated with a worsening of psoriasis, whilst others have shown that coffee may increase the efficacy of some drugs (methotrexate and sulfasalazine) used in the treatment of psoriasis.¹ A recent study showed that the effect of coffee on psoriasis is dose-dependent. Regular, moderate consumption (up to 3 cups per day)

alleviates symptoms and has an anti-inflammatory effect, whereas higher coffee consumption (>4 cups of coffee per day) makes symptoms worse.²

Comment

The observation that moderate coffee intake improves psoriasis symptoms, whilst higher levels of consumption make symptoms worse, is difficult to explain. However, if these findings were replicated in other studies, this could be of considerable importance from a public health perspective. In the meantime, it seems safe to say that moderate coffee consumption is not likely to be of any harm to psoriasis sufferers.

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Exercise hurdles

Individuals with psoriasis are known to have an increased risk of cardiovascular disease (heart attack and stroke). Despite longstanding recommendations that physical activity is important for heart health and fitness, most psoriasis sufferers, for reasons which are unclear, fail to engage in regular exercise. A recent UK study was an attempt to understand why this is and what might be done to correct it.¹



A total of 404 individuals (189 men and 215 women) with chronic plaque psoriasis and an average age of 49 years, were recruited. A clinical history was taken from each participant and detailed demographic and descriptive data were recorded. The severity of psoriasis was recorded using the Psoriasis Area and Severity Index (PASI) score and the psychosocial impact was assessed using the Dermatology Life Quality Index (DLQI). All subjects completed the International Physical Activity Questionnaire (IPAQ), a validated measure of the type and quantity of exercise performed by each participant.

Current guidelines recommend that all healthy adults aged 18-65 years should participate in moderate-intensity aerobic exercise, for a minimum of 30 minutes on 5 days each week, or high-intensity aerobic physical activity for a minimum of 20 minutes 3 days each week.

Results showed that, overall, 52.8% (n = 188) of patients with psoriasis aged 18-65 years and 66% (n = 37) of those aged > 65 years failed to meet the minimum physical activity recommendations. Moreover, significantly more women with psoriasis (60%) than men (45%) failed to meet the guidelines (the equivalent figures in the general population are 45% and 33% for women and men respectively). So, clearly, men are much more likely to engage in regular exercise than women.

As might be expected, rates of hypertension, diabetes and obesity were significantly higher in those not meeting current physical activity recommendations.

Most notably, this study also found – for the first time – objective evidence that as the severity and psychosocial impact of psoriasis increased (as measured by PASI and DLQI scores), participation in exercise (of all intensities) decreased. A number of different factors were identified as contributing to this, especially the visible symptoms of psoriasis, leading to embarrassment, fear of rejection, low mood, worries about clothing choices, skin sensitivity and problems with treatment. For the 21% of subjects with psoriatic arthritis, joint pain may be a major limiting factor to exercise participation, though this was apparently not assessed.

Comment

The low levels of physical activity found in this study, especially in women, are a concern. Patients with psoriasis have an increased risk of CVD, and regular exercise dramatically reduces that risk. Thus, promoting physical activity in individuals

with psoriasis should be a priority. However, this cannot be achieved unless the barriers to exercise – especially in women – are better understood. In this regard, women-only gyms and health clubs are much more common nowadays and many other clubs offer women-only gym sessions. Of course, this will not help men, who may also be the target of discrimination.

A major flaw with this study was that although 21% of the subjects had psoriatic arthritis, the authors did not evaluate this as a barrier to exercise. This seems a strange omission, given that for some individuals joint pain may be the barrier.

Reference

1. Auker L, Cordingley L et al. What are the barriers to physical activity in patients with chronic plaque psoriasis?. *British Journal of Dermatology* 2020; 183: 1094–1102

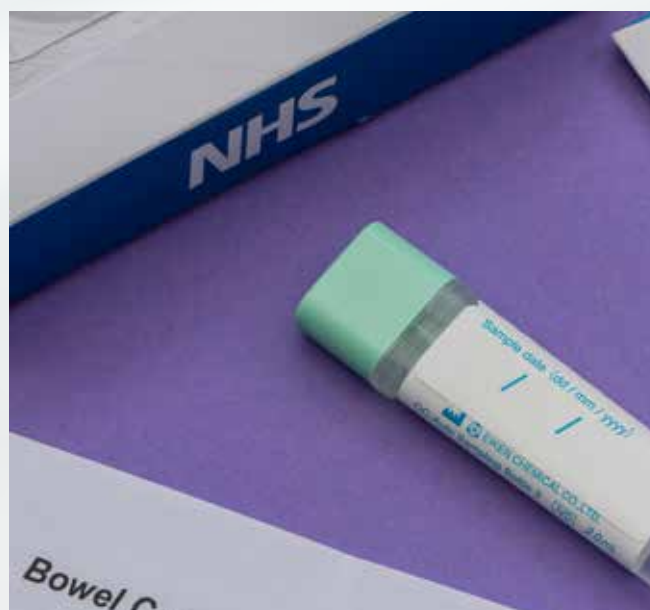
Bowel disease and psoriasis

Emerging evidence suggests that inflammatory bowel disease (IBD) – specifically Crohn's disease and ulcerative colitis – and psoriasis are strongly associated, sharing common genetic predispositions and immunological mechanisms. Given their close association, the question is whether IBD causes psoriasis, or psoriasis causes IBD. This large and extremely sophisticated German study was designed to answer exactly that question.¹

To this end, researchers used genetic information from 463,772 European individuals. Within this huge sample, researchers identified 12,882 cases of IBD and 5,621 cases of psoriasis. They found that genetic markers for IBD were associated with a higher risk of psoriasis and psoriatic arthritis. However, no association was found in the opposite direction. In other words, it is IBD that causes psoriasis rather than the reverse. These findings are consistent with a previous study, which showed that the prevalence of psoriasis in those with IBD was 4.2%, whereas the prevalence of IBD in patients with psoriasis was 1.2%.² It's worth noting, however, that because psoriasis often goes undiagnosed, it could be that patients with IBD actually have a higher prevalence of psoriasis than has been reported.

Comment

This is an impressive study of great importance, because it answers the question of the direction



of the relationship between IBD and psoriasis; it is IBD which causes psoriasis rather than the reverse. Importantly, neither psoriasis nor psoriatic arthritis have any causal relationship with IBD. Now, obviously, most patients with psoriasis do not have IBD and most with IBD do not have psoriasis, but when they do occur together, this study suggests that the direction is from IBD to psoriasis and not the reverse. The researchers cannot explain why this should be the case, but one might speculate that IBD in some way "primes" inflammatory pathways in the skin, resulting in the characteristic psoriatic plaques. From a practical perspective, patients with IBD and psoriasis are excellent candidates for a multidisciplinary approach to treatment, involving both gastroenterologists and dermatologists.

References:

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Campaigning

- **Our vision:** To see psoriasis and psoriatic arthritis managed in a positive way, more effectively.
- **Our mission:** To put people with psoriasis and psoriatic arthritis at the centre of care, deserving of recognition and effective management.
- **Our values:** To act ethically, with integrity on behalf of our constituent group and represent them fairly.
- **Our strategy:** To educate and empower people affected by psoriasis and psoriatic arthritis and those who provide the support and medical care, in order to optimise available resources more effectively.

To supporting our aims, we have developed a campaign called: ~ Care ~ Cause ~ Cure:

- **Care** = Support and education – information, website, training programmes/events.
- **Cause** = Research – funding relevant aligned projects.
- **Cure** = Facilitating the conversation to meet peoples' needs.

Our achievements:

- Around three-quarters of a million pounds provided to support research and training initiatives in psoriatic disease.
- Created the most comprehensive psoriatic disease specific website in the UK, with thousands of free to access items and pages.
- Developed a huge range of printed leaflets on the core aspects of the condition, with hundreds of thousands distributed free.

Promotional material

If you are thinking about supporting PAPAA or raising awareness on behalf of PAPAA about psoriasis and/or psoriatic arthritis, why not check out some of the merchandise we have available?



www.papaa.org/shop

- Trained multidisciplinary healthcare professional via our CPD accredited Psoriasis in Practice (PIP) programme, with many subsidised to access the training at no cost.
- Provided anonymised access to peer-support to those often desperate for someone to listen and hear their voice.
- More than 1,000 health care professionals provided with free patient support material regularly.
- Supported 3,500 UK pharmacies to provide free patient resource at the point of medicine delivery.
- Biannual journal called Skin 'n' Bones Connection regularly distributed since 1993 to patients and a wide range of healthcare providers.
- Engaged and represented patient views with UK regulators, including NICE, SMC, AWMSC and the MHRA, to provide input into new drug appraisals and regulatory affairs.
- Actively engaged across the most popular social media applications.
- Gathered real stories via our engagement group and PAPAA surveys with individual views and suggestions from lived-experience of psoriatic disease.
- Regular updates provided via an eNewsletter to a large dedicated subscription list.

We continue to furthering the ambition by:

- Raising visibility and profile of psoriatic disease.
- Providing research funding and support.
- Improving and expanding professional training.
- Further developing information and support material.
- Reviewing and keeping the website accurate.
- Proactively engaging with relevant agencies.

We have so much more to do, your continued support is much appreciated, see what others have done to support the campaign.

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