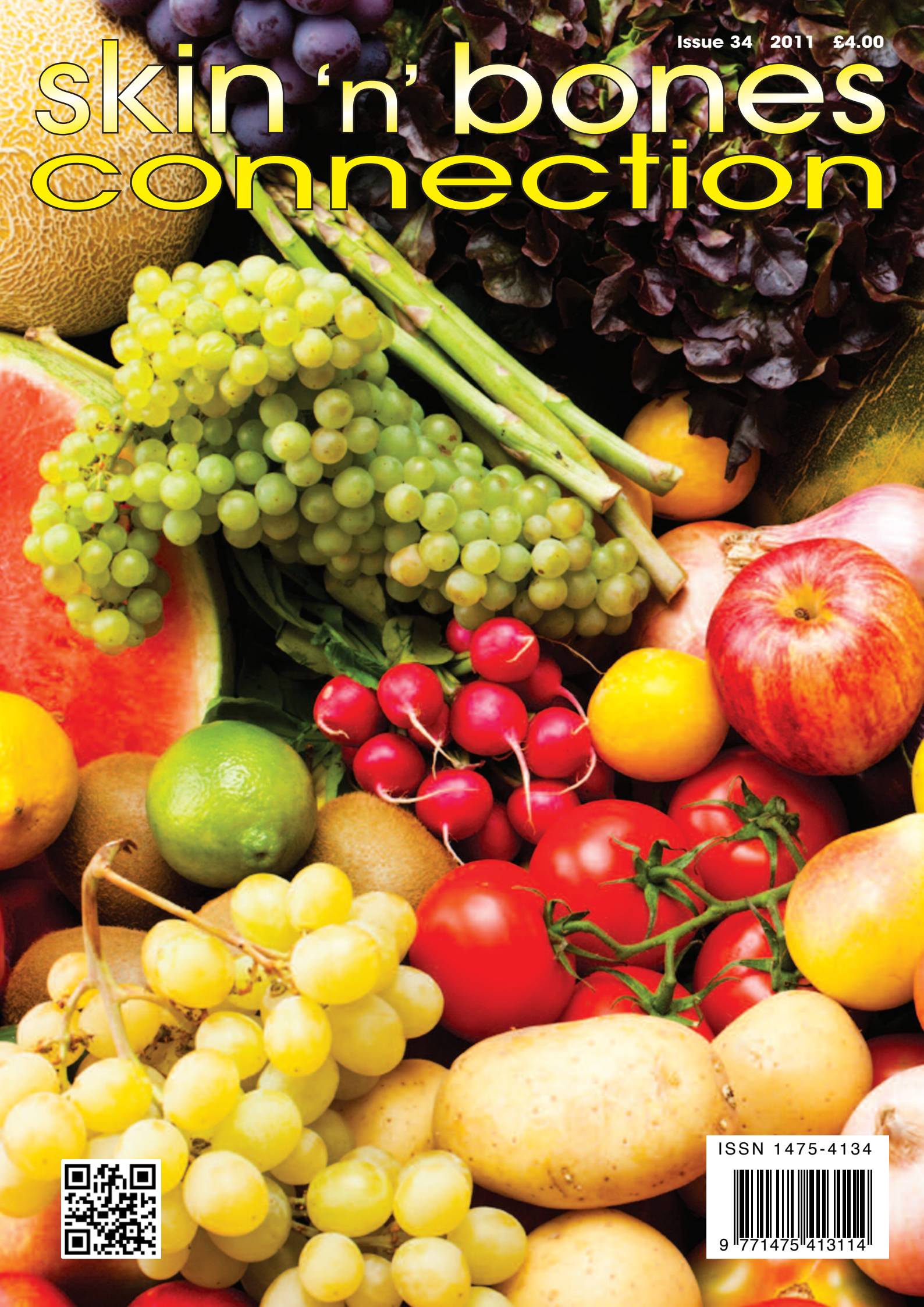
Issue 34 2011 £4.00

skin 'n' bones connection



ISSN 1475-4134

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Printing
Photolit Printing Ltd · St Albans

The Psoriasis and Psoriatic Arthritis Alliance is a Registered Charity No:1118192 and is a Company Limited by Guarantee, registered in England and Wales No: 6074887
Registered office: Acre House 11–15 William Road, London NW1 3ER

Dear Reader

Sometimes when living with a chronic condition, we might be forgiven for forgetting about our overall general health. On pages 10-12 we've been looking at issues relating to living well and where to get some good guidance.

Getting more involved in looking after your general health and being more involved can improve your understanding and potentially lead to better outcomes.

A recent meeting held in Newport (page 4) brought together a number of people with various skin conditions to discuss the issues that affect them. The meeting was the first in what is hoped to be a long-term process of encouraging people to influence the care they receive.

The process of getting people involved in decision making is being developed all around the UK and is often called PPI (Patient and Public Involvement). On pages 14 and 15 you will see that you can get involved in such work in Wales and Northern Ireland, which will provide important input into research and patient care.

Managing editor

Subscription rates:
United Kingdom - £12.00 (Renewal Rate £8.00) per annum - 2 issues
International - £24.00 (Renewal Rate £16.00) per annum - 2 issues

Publication Dates: May and November

Contribution Copy Dates: 28th February and 31st August

Skin 'n' Bones Connection is registered as a magazine ISSN: 1475-4134

Cover Photo:

A view of some of your five-a-day, the current recommendation for the number of portions of fruit and vegetables to be consumed each day.

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

Fish pedicures not recommended for people with psoriasis

In our last issue 33 of Skin 'n' Bones Connection, we reported that the Health Protection Agency (HPA) was going to assess all the evidence on risks associated with Garra rufa fish spa pedicure treatments.

After six months of investigation, the fish spa working group concluded that the risk of infection associated with Garra rufa fish pedicures is likely to be very low, although, those with weakened immune systems, or underlying medical conditions, including diabetes and psoriasis, are likely to be at increased risk of infection and so fish pedicures are not recommended for such individuals. The working group advised that operators of fish spas should not promote treatment to these groups.

'Important for salons to ensure the client has no underlying health conditions'

The investigation was triggered following a number of enquiries to the HPA from local environmental health practitioners, and a multi-agency working group was established to produce guidance for this spa treatment. The working group was led by the HPA and included experts from the HPA, Health Protection Scotland, the Health & Safety Laboratory and local authorities. The guidance has been endorsed by the Chartered Institute of Environmental Health and the Royal Environmental Health Institute of Scotland.

The report said that fish tank water has been shown to contain a number of microorganisms. Therefore, in a fish spa setting there is the potential for transmission of a range of infections, either from fish to person (during the nibbling process), water to person (from the bacteria that can multiply in water), or person to person (via water, surrounding surfaces and fish). However, the overall risk of infection is likely to be very low, if appropriate standards of hygiene are adhered to.

Dr Hilary Kirkbride, consultant epidemiologist at the HPA, said: "Provided that good standards of hygiene are followed by salons, members of the public are unlikely to get an infection from a fish spa pedicure, however the risk will be higher for certain people.

"This is why we feel it's important for salons to ensure the client has no underlying health conditions that could put them at risk, and that a thorough foot examination is performed, to make sure there are no cuts, grazes or existing skin conditions that could spread infection.

"Anyone considering a fish pedicure can help reduce the risk of infection – both to themselves and others – by taking simple precautions. Allowing any cuts or infections you may have on your feet or legs to heal before having the treatment, and waiting at least 24 hours after having a leg wax or shaving, will minimise your chances of catching anything. If you do experience any ill effects after the treatment, you should visit your GP."

Dr Paul Cosford, director of health protection services at the HPA, added: "As with any beauty salon, it's really important that strict standards of cleanliness are followed, to ensure that the risk of infection is kept to a minimum. If a member of the public is concerned about the level of cleanliness of a salon they visit, they should report this to their local environmental health department."

About the HPA

The Health Protection Agency is an independent UK organisation that was set up by the government in 2003 to protect the public from threats to their health from infectious diseases and environmental hazards. In April 2013, subject to the usual approvals procedures for establishing new bodies, the Health Protection Agency will become part of a new organisation called Public Health England, an executive agency of the Department of Health. To find out more, visit our website:

For more information
www. hpa .org.uk

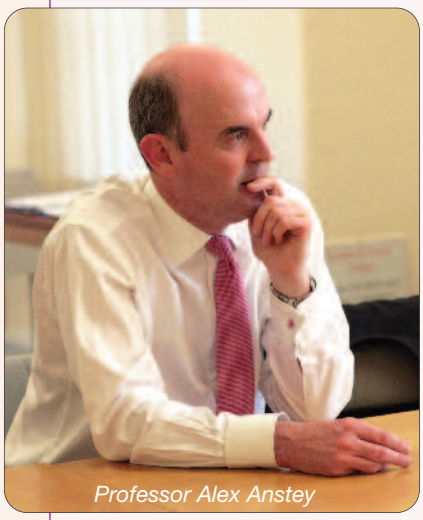
Source:
The Health Protection Agency Press release 18 October 2011

Gwent dermatology patient panel

The NHS dermatology department in Gwent has established a good reputation for excellence in service delivery. Important ingredients to account for this success are strong leadership, strong teamwork, excellence in education and excellence in research. Despite this, more needs to be done to improve patient services.

How does patient advocacy work at a local level for service delivery?

Patient involvement in local service delivery decisions is slowly becoming the norm in the NHS. There is much talk about *patient-centred services*, but more needs to be done if patient advocacy is to influence the way decisions are made about local dermatology services. The last decade has seen all healthcare organisations set up lay panels whose role is to give the patient perspective. The next step in this process is to build on this infrastructure by creating speciality-specific lay panels. Thus, decisions about healthcare delivery will be informed by the patients for whom these services are intended.



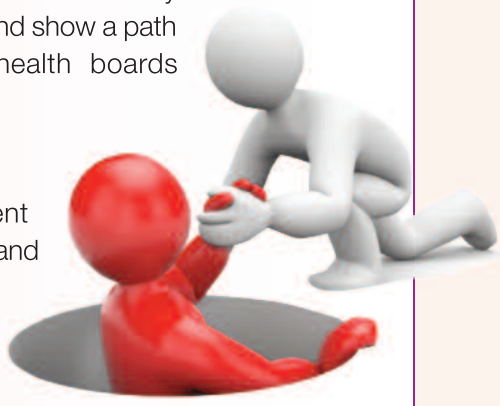
Professor Alex Anstey

Patient advocacy is needed if service delivery is to be shaped to respond appropriately to local demand. The Welsh Assembly Government is committed to transforming the NHS in Wales. Central to this transformation is recognition of the need for the NHS to maintain an intense focus on the patient experience; this will, it is hoped, provide unity of purpose across NHS Wales. The patient experience is placed centrally in health service policy. At a local level there needs to be engagement with patients if this ambitious agenda is to be realised.

First step

An initial patient panel meeting was held in September by the dermatology department in Gwent to launch an independent skin care panel. Invitations were sent to people who attend clinics run by consultant dermatologist Professor Alex Anstey at the Royal Gwent Hospital. The meeting was informal, with time for those who attended to learn about patient advocacy and the importance of becoming involved in shaping and challenging the services provided within the NHS. It is hoped that further meetings will be held to formally establish the group and show a path that other Welsh health boards could follow.

Speakers at the meeting: Mayda Thomas (Skin Care Cymru), David Chandler (PAPAA) and Lynne Thomas (Involving People).



Get involved

If you are a patient with a skin condition and wish to contribute to this process of patient advocacy in Gwent, please contact Academic Dermatology to register your interest. You will be asked to identify which role or roles you feel best equipped to take on.

Contact details:
Academic Dermatology
C Block, St Woolos Hospital, Stow Hill,
Newport, NP20 4SZ

Telephone: 01633 238145 or 238561
Email: admin@academicdermatology.co.uk

SOURCE:>> **Abridged and amended from www.academicdermatology.co.uk Accessed: 20 October 2011**

As reported in Skin 'n' Bones Connection 33, PAPAA has become an Information Standard (IS) member, which allows us to place the IS logo on our material.

What is *Psoriatic Arthritis?* is one of 15 patient information leaflets in our range included within the scope of our IS membership.

The leaflet has gone through a rigorous process of updating and revision to abide by the standard, which says that the information must be:

- Accurate
- Impartial
- Balanced
- Evidence-based
- Accessible
- Well-written

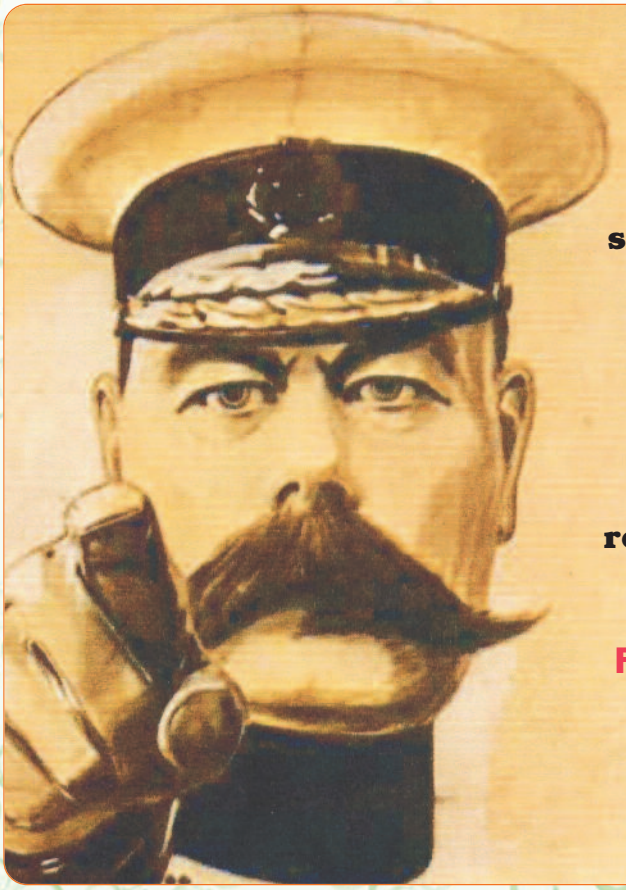
We are grateful to Dr William Tillett, research registrar at the Royal National Hospital for Rheumatic Diseases in Bath, for carrying out the evidence research and providing revised, updated text.

We are also grateful to those members of PAPAA and professional colleagues who have made useful and constructive comments.

If you would like a copy of the new revised version, please let us know or you can order it for free from our online shop at **www.psoriasis-shop.org**

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

We are now in the process of systematically revising the other leaflets in our range.



We need your help

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

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

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

Online CBT programme

As reported in Skin 'n' Bones Connection (issue 30), PAPAA has been funding the research and development of an online CBT training programme called eTIPs – electronic Targeted Intervention for Psoriasis. The study has now been completed and a research paper is currently being prepared for publication by Dr Christine Bundy and her colleagues at the University of Manchester.

eTIPs is an online, menu-based, interactive programme which uses a multi-media format including text, videos, audio clips and graphics. This means people can choose the order in which they interact with the programme and work through it in the privacy of their home.

The programme uses the principles of cognitive behaviour therapy – a popular form of psychological therapy which focuses on helping individuals to understand that the way they think about a situation can affect the way they feel and act. CBT requires patients to practise exercises designed to help them understand their personal patterns and to improve psychological wellbeing and so manage their psoriasis better.

The programme starts with an introductory section which provides details about the different types of psoriasis and treatments available, cognitive behaviour therapy and the eTIPs programme. People then work through a further five sections which target psychological symptoms highlighted as important to psoriasis patients – self-esteem, thinking styles, low mood and depression, stress and tension, coping.

The programme is now open and available for anyone to try at:

www.etips.org.uk

Help us to make it work

We are looking for people to help us with the public version; we would like to find out which elements you like, which you dislike and any barriers which would stop you from completing all six sections via an evaluation.

The programme requires the participant to complete a simple registration stage, which will then generate a unique login password within 48 hours of submission. If you would like to gain immediate access please call us and we will be able speed up the process.

www.etips.org.uk

"Patchy and slow" is how the Health Service ombudsman, Ann Abraham, describes the progress the NHS is making to improve the way it deals with patients' complaints. In her latest report on NHS performance she warns that "The NHS is still not dealing adequately with the most straightforward matters" and that too many minor disputes are escalated to her office before they are resolved.

A report published in October called *Listening and Learning: the Ombudsman's review of complaint handling by the NHS in England 2010-11* features previously unpublished information about complaints that the NHS has failed to resolve locally. It reveals which NHS trusts and which regions in England generated the most complaints to the ombudsman's office (the second and final stage in the NHS complaints system) during the year. It also highlights the most common reasons for people to complain, and includes complaints information on every trust across the country.

The ombudsman's office received more than 15,000 complaints about the NHS in 2010-11. As the stories in the report illustrate, last year relatively minor disputes about unanswered telephones or mix-ups over appointments ended up with the ombudsman because of knee-jerk responses by NHS staff, and poor complaint handling.

In particular, the ombudsman highlights an increased number of complaints about the removal of patients from their GP practice's list, sometimes without warning. Last year, 21 per cent of all complaints about GPs investigated by the ombudsman were about patient removals, a rise of 6% compared to the previous year. In one case, a terminally ill woman was removed from her GP's list following a dispute between the practice and her daughter. In another case, a woman was removed from her GP's list after a 'simple disagreement' about unanswered telephone calls. As GPs prepare to take on greater responsibility for commissioning patient services, the report warns that some are failing to handle even the most basic complaints appropriately.

Patients and their families need to be encouraged to speak up and complain. Ann Abraham explains:

"There is a growing recognition that patient feedback is a valuable resource for the NHS at a time of uncertainty and change. It is a resource that is directly and swiftly available, covering all aspects of service, care and treatment. But when feedback is ignored and becomes a complaint, it risks changing from being an asset to a cost."

The report also reveals that in 2010-11:

- London and the North West were the two regions that generated the most complaints.
- more complaints were received about hospital, specialist and teaching trusts (acute) than any other group – 6,924 complaints (46%).
- primary care trusts and GPs accounted for 18% and 17%, respectively, of all complaints.
- more complaints were made about Heart of England NHS Foundation Trust than any other.
- the two most common reasons people gave for being dissatisfied with how the NHS had handled their complaint were poor explanations and no acknowledgement of mistakes.
- 230 complaints were resolved quickly and informally through the ombudsman's intervention, and a further 351 complaints were accepted for investigation
- the ombudsman secured nearly £500,000 for patients to help remedy injustice caused by poor care or poor complaint handling.

About the ombudsman

The role of the ombudsman is to consider complaints that government departments, a range of other public bodies in the UK, and the NHS in England have not acted properly or fairly or have provided a poor service. The aim is to provide an independent, high quality complaint handling service that rights individual wrongs, drives improvement in public services and informs public policy.

The full report Listening and Learning: the Ombudsman's review of complaint handling by the NHS in England 2010-11 is available at:

www.ombudsman.org.uk/listening-and-learning-2011.

SOURCE>>: www.ombudsman.org.uk
Media release
18 October 2011

NHS Future Forum

The independent NHS Future Forum, a group of the country's top health experts, has recently published its interim advice on integrated care, patient information and public health in a modern NHS, after listening to thousands of NHS staff, patients and the public as well as voluntary sector organisations.

The advice follows a request from the Prime Minister earlier this year, for the NHS Future Forum, to continue its successful dialogue and consider certain key themes with staff, patients and the public.

The interim advice and recommendations published in November are aimed at informing the 2012/13 NHS operating framework and the plans around a new public health system.

The advice stresses that information about health and social care services must be published in a transparent and usable form and patients must have better access to health care records. It also calls for a national partnership across the NHS and public health.

The final reports, which will also include recommendations on education and training, will be published towards the end of 2011.

In his meeting with the NHS Future Forum, health secretary Andrew Lansley said:

''It is clear that the approach taken by the NHS Future Forum, both during the listening exercise and in its current phase, has provided us with invaluable feedback and insight from patients and NHS staff on what the NHS needs to do to improve outcomes and put patients at the heart of everything it does.

''The interim advice and recommendations are very useful and we will take them into consideration before we publish the 2012/13 NHS operating framework and further details about the new public health system.

"This shows the importance of engaging with patients and staff to ensure services are designed around patients. I look forward to the Forum's final report later in the year.''

SOURCE:>> Department of Health
Press release
17 November 2011

Tregalizumab a new trial shows promise

In a recent report 49 patients with chronic plaque psoriasis were enrolled into a trial of tregalizumab. Tregalizumab is a drug which has an effect on the immune system (an immunomodulator) and is in the same class as other biological treatments.

The drug in the trial was given as subcutaneous injections or intravenous infusions once weekly for 8 weeks. After the treatment period, the patients were observed for further 12 weeks without tregalizumab treatment, 71.4% of patients experienced at least a 50% improvement in psoriasis signs and symptoms as measured by the psoriasis area severity index (PASI). To make up the PASI score, the three features (redness, thickness, and scaliness) of psoriatic lesions are each assigned a number from 0 to 4 with 4 being worst. The extent of involvement of each region of the body is scored from 0 to 6. Adding up the scores gives a range of 0 to 72.

Further trials need to take place and safety data gathered.

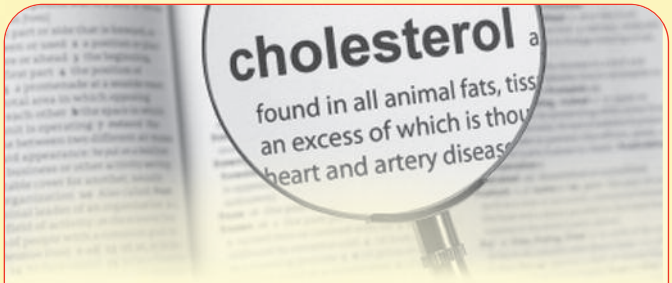
Calcipotriol cream discontinued

Calcipotriol cream (brand name Dovonex®) has been withdrawn from the market as part of a "rationalisation" of the product range by the manufacturer. Therefore from the 1st October 2011 only 120g of ointment will be available.

The manufacturer has stated that the withdrawal is not related to any safety or quality issues.

The product will still be available and can be issued against prescriptions until stocks are exhausted.

If you have any concerns about your treatment or issues related to this medication, talk to your general practitioner (GP) or other healthcare provider.



Psoriasis and cholesterol

Initial findings from a study in the US have suggested that the inflammation caused by psoriasis may trigger changes in an individuals' cholesterol, including weakening the function of high-density lipoprotein (HDL), which is often called the good cholesterol.

If the initial study results are confirmed it could help to explain why people with moderate to severe psoriasis are at greater risk of related cardiovascular problems.

''Anecdotally, many researchers have observed that HDL levels may be lower in states of inflammation, such as rheumatoid arthritis, psoriasis and even obesity,'' study author Dr. Nehal Mehta, director of the Inflammatory Risk Clinic in the preventive cardiology program at the University of Pennsylvania, said in a university news release.

''However, these new findings suggest that in addition to lower levels, chronic inflammation associated with conditions like psoriasis may change the composition and decrease the function of HDL as well,'' Mehta added.

While the study uncovered an association between psoriasis and HDL function, it did not prove a cause-and-effect relationship, and the researchers say more study is needed to confirm the link.

SOURCE:>> **University of Pennsylvania News release November 2011**

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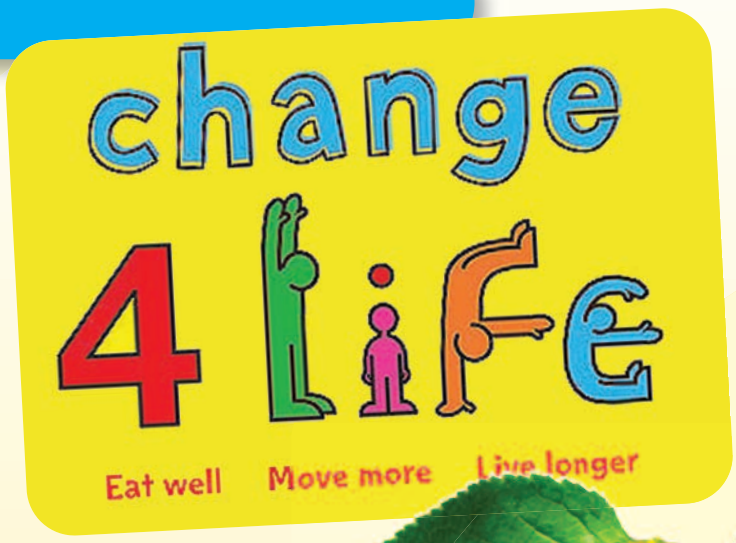


We seem to be bombarded with messages these days with the importance of leading a healthy lifestyle; it does make sense to eat properly, relax, avoid stress, get the work balance right, eat proper foods, get your five-a-day, drink in moderation and be happy! But as we all know, if only life was that simple.

It can all seem so saturating, and in the end, all the pressures from the media, health professionals, the diet industry, your friends and family, that you may just have a brief meltdown, give in, thinking what's the point, and go for the cream cakes or a nice, smooth chocolate bar!

So, where do you start to get the right advice and begin to understand what is the best thing to do, particularly if you live with a chronic disease such as psoriasis, or psoriatic arthritis?

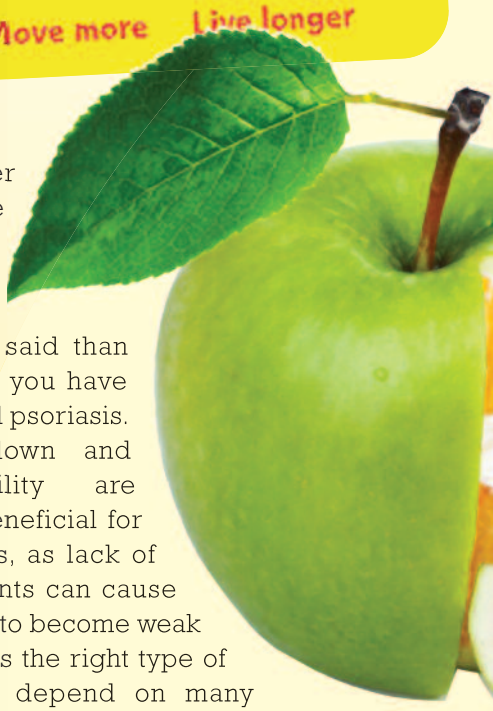
Well, a good place to start might be your general practitioner, particularly if you are considering radical changes to your lifestyle. It is always a good idea to make sure that these changes don't cause any general health problems or interference with your current treatments.

Your GP might recommend that you think about why you want to change your lifestyle and may suggest you look at the NHS Choices or Change 4 Life websites, or refer you to an allied healthcare professional.

NHS Choices is an excellent place to start; the comprehensive site covers many health issues and has sections which signpost to other trusted websites and sources of information. There is also a link to the Change 4 Life site.

The Change 4 Life campaign was launched in September 2008, with a commitment of £75 million to develop an ambitious new advertising campaign to help individuals and families eat well, move more and live longer, the campaign has been widely promoted via TV, billboards, magazines and internet.

You can learn a great deal from the Change 4 Life site; the key messages are that changing doesn't have to be a chore and the health benefits can be enormous. The idea of cutting out things you like often makes change hard to sustain, so just reducing portion sizes and monitoring food intake can provide enough of an incentive to see that small changes can have an impact.



One of the other messages, is to take more exercise. At this point; you may be thinking, that even that is easier said than done, particularly if you have psoriatic arthritis and psoriasis. Keeping weight down and maintaining mobility are recommended as beneficial for people with arthritis, as lack of movement of the joints can cause stiffness and muscles to become weak and wither. So what is the right type of exercise? This will depend on many differing issues, including other health conditions you may have (co-morbidities). These could include high blood pressure, diabetes etc.

Before embarking on exercise it is always worth seeking advice about the right type of exercise foryour circumstances and what is likely to help your mobility and avoid making joints worse. Physiotherapists are experts in the examination and treatment of muscles and joints and are available in many areas of the NHS and also within private practice. Ask your GP about services local to you; the Chartered Society of Physiotherapist website has a section where you can locate a physiotherapist in your area. PAPAA also has a booklet called *Physiotherapy and Exercise: Psoriatic Arthritis* which is available free as hard copy or via the website. The booklet provides a comprehensive explanation and sample exercises that might help you to maintain joint movement.

The other issues that might cause a barrier to exercise could include extensive psoriasis – feelings of embarrassment and the general issues caused by communal changing rooms at gyms and swimming pools do create problems for many people. There is not an easy answer to overcoming these feelings, but dealing with the psychological impact of psoriasis can improve overall wellbeing. The electronic Targeted Intervention for Psoriasis (eTIPs) programme was designed to try to help change these feelings and provide methods of overcoming the anxiety that accompanies being in a social situation where the psoriasis is causing negative thoughts. A report about the eTIPs programme is on page 6.

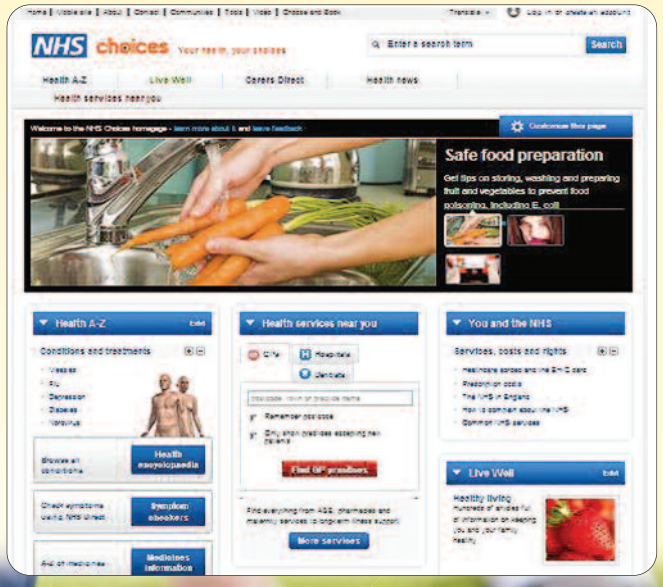
Another consideration for maintaining a healthy lifestyle might be the levels of alcohol consumed; with some treatments for psoriasis and psoriatic arthritis, you might be advised to cut down or abstain from drinking alcohol. This again may be hard for many people to do, as a recent survey by BUPA revealed that British people have the highest rates of alcohol consumption in the world and are

least likely to want to cut down (see page 16 for article). To understand the risks of too much alcohol consumption there are a number of useful websites that explain the units and effects of overindulgence.

The NHS recommends men should not regularly drink more than 3-4 units of alcohol a day. Women should not regularly drink more than 2-3 units a day ('regularly' means drinking this amount every day or

most days of the week). A unit is dependent on strength of alcohol content. For example, one pint of standard lager (4% volume alcohol) is 2.3 units, 2 glasses of white wine (175 ml per glass measure - 12% volume of alcohol) is 3 units and single measure of gin 25ml - 37.5% volume) is 1 unit. The calorie content of a single pint of lager is 187 calories. Therefore it is easy to see how reducing alcohol intake, even by small amounts can have an impact on weight and overall health. Which doesn't mean cutting it out completely, unless you have been specifically advised to do so by your doctor.

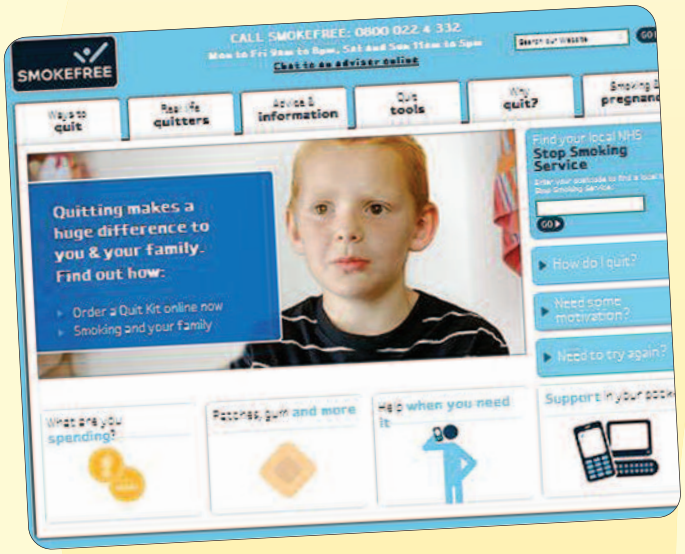
The issue of smoking has been well documented and reported as having a major impact on health and a major cause of lung cancer. Changing other lifestyles elements, including eating five-a-day of fruit and vegetables or taking more exercise means very little if you continue to smoke. In fact a report in 2007



HEALTHY HABITS

following a study of 79,000 nurses in the United States reported that psoriasis was much more prevalent amongst people who smoked (78%) than those who had never smoked, but even more interesting is that it takes 20 years to go back to normal after quitting.

There are a number of services available to help quit smoking, and the NHS Choices website has links to useful resources. Smokefree is run by the NHS and has video clips of real-life quitters to encourage and demonstrate the benefits. The site also has the option to chat to an advisor online, which allows participants to ask questions directly to an advisor.



You can live a normal life and adopt a healthy lifestyle. Common sense is the key word here. If you want to try a diet, then do your background research, check with your doctor, even see a dietician and do things properly and in a measured way.

Please bear in mind that by eating and drinking in moderation, adequate exercise that suits your needs (whether it's extreme sports or just going for nice walk to wind down) will help you to maintain your health levels on all fronts. Little is better than nothing, and it's true, sometimes taking the stairs instead of the lift does make a difference. Little by little, being healthy doesn't and shouldn't be a chore, but a part of your life that you adopt and don't realise you're doing. It should come as naturally as you can make it. Cutting out all your favourite foods at once is not the answer; do it gradually, so it is not a shock to your body or your cravings! Swap foods from processed sugars to natural sugars, by eating fruit for example. Make cooking fun again, experiment with foods, get the kids involved – strange as it may seem, they sometimes know more these days about the values of foods than we do. Do you live to eat or do you eat to live? Reinvent yourself with food, exercise and your lifestyle. Sometimes it's good to take a step back and look at how we do things or could improve even the smallest of things to make a huge difference.

Life is by no means simple, but by trying to address some lifestyle issues in a clear, common-sense way, may inspire you to look at what your doing and see if there are any small changes you can make, that will bring benefits in the near future.

Useful resources and contacts:

NHS Choices
www.nhs.gov.uk

Change 4 Life
www.nhs.uk/change4life

The Chartered Society of Physiotherapy
14 Bedford Row, London, WC1R 4ED
Tel: 020 7306 6666
www.csp.org.uk

Physiotherapy and Exercise:
Psoriatic Arthritis – booklet
www.papaa.org

electronic Targeted Intervention for Psoriasis (eTIPs)
www.etips.org.uk

Smokefree
www.smokefree.nhs.uk

Free NHS Smoking Helpline:
0800 022 4 332
Mon to Fri 9am to 8pm,
Sat and Sun 11am to 5pm

Reference:

Smoking and the Risk of Psoriasis in Women Nurses Health Study II: Setty A R, Curhan G, Choi H K; The American Journal of Medicine, Volume 120, Issue 11 (November 2007).

The Scottish Parliament

Within the Scottish Parliament there are a number of cross-party groups (CPGs) which are designed to provide an opportunity for members of all parties, outside organisations and members of the public to meet and discuss a shared interest in a particular cause or subject.

The Psoriasis and Psoriatic Arthritis CPG was formed to raise awareness, improve public understanding and knowledge and work towards improving services for the needs of people in Scotland who suffer from psoriasis and psoriatic arthritis.

How do cross-party groups operate?

The operation of CPGs is regulated by Section 6 (Volume 2) of the Code of Conduct for MSPs which outlines the procedures for establishing a CPG and sets out the framework for their operation.

The framework set out in the Code of Conduct for the operation of CPGs is not prescriptive in relation to the procedures to be followed by the groups and groups may determine their own procedures, provided that these procedures are in line with the general rules set out in Section 6.

For further information about dates and attending meetings contact:

Dave Thompson MSP
Room M3.09
Scottish Parliament
Edinburgh EH99 1SP

0131 348 5325
01349 864701

Skin Care Cymru

Skin Care Cymru is an organisation that represents the interests of people in Wales who suffer from a skin condition. The organisation seeks improvements in care for people affected by any skin condition and to educate and inform relevant professional bodies, the public and media about the needs of people affected by such conditions.

The aims of Skin Care Cymru are:

- To work towards the improvement of healthcare for people suffering from any kind of skin disease by making recommendations and looking for improvements in dermatological services to the Welsh Assembly Government, and directly to healthcare providers
- To educate and inform the public about skin disease and effective treatments through media campaigns and organised events
- To provide a strong and high profile voice for dermatology patients and to support other organisations and professional bodies to pursue these objectives.

If you wish to learn more about the work of Skin Care Cymru or get involved:

www.skincarecymru.org
email: info@skincarecymru.org
Write to:
Skin Care Cymru, PO Box 612,
Swansea SA1 9GH

Involving people

Involving People is the national project for active patient and public involvement in health and social care research in Wales. We are part of the National Institute for Social Care and Health Research Clinical Research Centre (NISCHR CRC) and have been operating since 2006.

Involving People has two main functions: to help researchers find people to become involved in the development of their studies (reviewing patient information sheets, joining research development groups etc.) and to help patients, carers, service users and members of the public become actively involved in appropriate research studies, based on their experiences and interests.

We coordinate a network of over 200 members from all over Wales, enabling us to recruit locally or nationally. We work closely with NISCHR Registered Research Groups and Trials Units, Universities in Wales and Health Boards. Recently, we have engaged with a patient panel focussing on research into skin conditions.

The people on our network are ready and willing to get involved. In addition, we provide training to our network members in Getting Involved & Influencing Research, Introduction to Basic Research Methods, Induction to Involving People (including the role of the service user), Good Clinical Practice in Research and Language Awareness in Research.

We believe that there are many benefits to actively involving people in research. Grant applications now ask for evidence of user involvement in the study development and study materials developed with service user input are often more user-friendly. A fresh pair of eyes is a great quality check and not forgetting that people are experiential experts and a valuable source of information.

The crucial thing is to involve people as early as possible in the process to get the maximum benefit from their input.

''Having a Patient and Public Involvement (PPI), representative at monthly management team meetings is very important. Firstly, clinicians and nurses attend these meetings and it allows us to have the equally important patient perspective on plans. Secondly, it reminds the core project team to use everyday language when designing projects that will involve the general public and often highlights important points that we might have overlooked had we not had patient representation.'' Researcher.

If you would like more information, please contact:
Involving People, 3rd Floor,
12 Cathedral Road, Cardiff, CF11 9LJ.
T: 029 2019 6806

E: involving.people@wales.nhs.uk
www.involvingpeople.org.uk

About the NICRN

The Northern Ireland Clinical Research Network (NICRN) has been established to support the clinical research community in Northern Ireland.

The aim of the NICRN is:

- To promote research within Northern Ireland
- To develop close partnerships and productive working relationships with key individuals and groups across the network and the wider research community
- To ensure that targets, including accrual of patients into trials, are achieved and maintained.

What does the NICRN do?

- Maintain a portfolio of network studies
- Assist with processes involved in setting up a study, in particular ethical, regulatory and local research governance approval for clinical trials
- Facilitate training and education
- Ensure that research opportunities are maximised within available resources.

Frequently asked questions

What is clinical research?

Clinical research aims to find out the causes of human illness and how it can be treated or prevented. This type of research is based on examining and observing people with different conditions and sometimes, comparing them with healthy people. It can, also involve research on samples of blood or other tissues, or tests such as scans or X-rays. Clinical researchers will also sometimes analyse the information in patient records, or the data from health and lifestyle surveys.

Patient and public involvement

As a patient, carer or as a member of the public you can help research. You can participate in a clinical or other well designed study. You can give your views. You can actively get involved with us to help shape research. We are keen to hear and learn from you.

The Department of Health's national strategy puts patients at the centre of all NHS-related activity. To ensure that 'patient benefit' is not simply based on the views and options of research professionals and clinicians, the national strategy, highlights the importance of involving patients, carers and the public at all stages of the research process.

Patients and public can be involved:

- As patients/participants voluntarily taking part in clinical or other well designed studies
- As patients and public members working with researcher professionals and clinicians (eg doctors, nurses) and getting actively involved in the different stages of research and related activities.

If you are interested in learning more contact:

NICRN Co-ordinating Centre
Rm 2007 - 2nd Floor
King Edward Building, The Royal Hospitals
Grosvenor Road, BELFAST BT12 6BA
www.nicrn.hscni.net/

Or visit:

The National Institute for Health Research
www.crncc.nihr.ac.uk/ppi

Alcohol warning

A recently published survey is warning people in the UK to face up to the realities of excessive drinking as research reveals that despite having one of the highest rates of alcohol consumption in the world, they are the least likely to want to cut down their intake.

The international Bupa Health Pulse survey is an annual healthcare survey. In 2011, 13,000 people were surveyed in twelve countries; the UK, Spain, Australia, Mexico, India, the US, Brazil, China, New Zealand, Saudi Arabia, Hong Kong and Thailand. The survey found that people in the UK are over a third (41%) more likely to drink alcohol than the international average. They are also twice as likely to describe themselves as 'regular drinkers', with almost 1 in 10 (9%) admitting to drinking every day – over double the international average.

But despite the proven link between excess alcohol consumption (described by the chief medical officer as more than 2-3 units a day for women or 3-4 units for men) and a range of life-threatening health conditions, more than 1 in 3 of UK citizens who drink (38%) say they don't want to change their behaviour. Internationally, almost 3 in 4 of drinkers have admitted they would like to cut down.

Assistant medical director for Bupa, Dr Layla McCay, said: ''This is a worrying observation, which implies that people in the UK, are particularly resistant to change when it comes to drinking habits. Whether, that is due to a lack of awareness about alcohol effects or whether we are simply in denial, there is clearly more work to be done to raise awareness of the associated risks and the real impact it can have on lives.

"Excessive drinking carries several health risks, including heart disease, stroke, liver disease, many types of cancer, and even diabetes. Something needs to be done immediately and we need to challenge the social norms – social lives too often revolve around drinking and it is important that we work towards coming up with healthier alternatives. It's not about total abstinence, but it is about drinking responsibly and being aware of the effects that heavy drinking can have.''

Chief executive of Drinkaware, Chris Sorek, said: ''There is always an excuse to drink, but there are plenty of reasons to cut down too. It can be easy to drink more than you intended, by not being aware of the units in your favourite drink or pouring large measures at home. However, drinking can affect your sleep patterns, meaning you wake up feeling stressed and tired the next day.

''Regularly drinking over the daily guidelines can lead to more serious health harms including alcohol-related liver disease, which has no warning signs. Alcohol is also the second biggest risk factor for cancer after smoking - responsible for cancer of the breast, liver, bowel and mouth."

More facts and advice about alcohol visit: www.drinkaware.co.uk

SOURCE:>> **Press release: Bupa Pulse Survey 2011**

Paracetamol warning

In a recent study repeatedly taking slightly too much paracetamol over time can cause a dangerous overdose that is difficult to spot, but puts the person at danger of dying. Patients may not go to hospital reporting the overdose, but because they feel unwell. This clinical situation needs to be recognised and treated rapidly because these patients are at even greater danger than people who take single overdoses.

These so-called staggered overdoses can occur when people have pain and repeatedly take a little more paracetamol than they should.

"They haven't taken the sort of single-moment, one-off massive overdoses taken by people who try to commit suicide, but over time the damage builds up, and the effect can be fatal," says Dr Kenneth Simpson, who publishes the findings of a recent research project in the British Journal of Clinical Pharmacology.

The problem is that doctors normally assess how much danger an overdose patient is in when they arrive at hospital by taking a blood sample and finding out how much paracetamol is present. In the case of a single dose overdose, the blood sample gives valuable information, but people with staggered overdoses may have low levels of paracetamol in their blood even though they are at high risk of liver failure and death.

Working in the University of Edinburgh and the Scottish Liver Transplantation Unit, Scotland, Dr Simpson and his team analysed data from 663 patients who had been admitted to the Royal Infirmary of Edinburgh between 1992 and 2008 with paracetamol-induced liver injury. They found that 161 had taken a staggered overdose, usually to relieve a variety of common pains, such as abdominal or muscular pains, headache and toothache.

"On admission, these staggered overdose patients were more likely to have liver and brain problems, require kidney dialysis or help with breathing and were at a greater risk of dying than people who had taken single overdoses," says Simpson. The problem is also worse for people who arrive at hospital more than a day after taking an overdose - they are also at high risk of dying or needing a liver transplant.

"Staggered overdoses or patients presenting late after an overdose need to be closely monitored and considered for the paracetamol antidote, N-acetylcysteine, irrespective of the concentration of paracetamol in their blood," says Simpson.

Because measuring the paracetamol in the blood is such a poor assessment of the patient's status in staggered overdoses or delayed presentation, he believes that doctors urgently need to find new ways of assessing whether a patient can be sent home, needs medical treatment to counteract the paracetamol, or needs to be considered for a liver transplant.

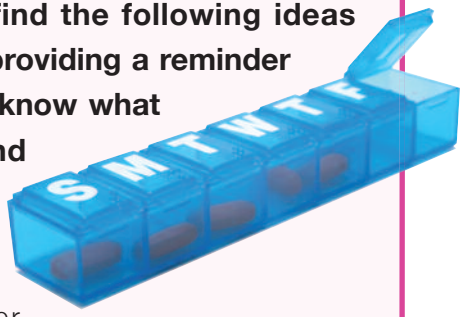
If you are worried about the effects of taking paracetamol or any other medications, talk to your healthcare provider.

SOURCE:>>

News release
British Journal of Clinical Pharmacology
November 2011

Pill reminder

If you are worried about remembering to take your medication or worried about taking too much, you might find the following ideas useful as ways of providing a reminder or an easy way to know what you have taken and when.



The most traditional method is to use a tablet box organiser. These have separate compartments, which have the day of the week marked. You dispense your tablets into the compartments and this provides a simple solution in a busy life. Chemists have a selection of these types of products and there are many outlets on the internet that offer differing sizes and styles.

An advancement recently, are smart phone applications (Apps) which provide a pillbox alert/alarm to remind you during the course of the day what you need to take and when. These can be downloaded via your phone or from iTunes.

Letters

Dear PAPAA,

My name is Suzina Blackman and I am a fully qualified & insured YMCA chair-based exercise and OTAGO (balance & stability) instructor.

I would like to take this opportunity to tell you about the seated exercise classes which I run in Welwyn Garden City & Hatfield, Hertfordshire and how they may benefit sufferers of psoriatic arthritis. They are just £2 per person and we always stop for a cuppa and a chat afterwards. Classes are open to men and woman of all ages and abilities.

The entire class may be performed sitting down although, there are sections where you can stand if you prefer to.

Seated exercise is the safest, most effective way of strengthening functional muscle groups. It is totally non-impact. Even for more active individuals there are certain exercises and certain days when chair support may be appropriate or provide a sensible solution. Mastering basic techniques seated, provides much greater skill and confidence before performing them standing. Regular chair-based exercise classes may help to:

- Increase joint mobility
- Increase muscle strength and tone
- Improve flexibility and full range of movement
- Improve function
- Improve core strength
- Improve confidence and self-esteem
- Improve sleep patterns

They are held: Monday 2.30-3.30pm at Barndicott Hall, Moors Walk, WGC, AL7 2BX. Wednesday 2-3pm at Glebe Court, Brain Close, Hatfield, AL10 8BY. Thursday 10.15-11.15am at Christchurch Baptist Church, 110 Parkway, WGC, AL8 6HN (fresh cooked lunches are served 12-2pm term time only). Thursday 2-3pm Home Meadow Communal Hall, Peartree Lane, WGC, AL7 3BA

Contact Suzina Blackman for more information;
Phone 07930 302 102
email: suzina@homefitnessherts.co.uk
website: www.homefitnessherts.co.uk
and click on 'chair based classes'

Dear PAPAA,

In response to your article "Ichthyotherapy for psoriasis" in Skin `n` Bones issue 33: I went to visit my grandchildren in March as a Mother`s Day present, my daughter had arranged for me to try this as I struggle with painful feet due to my PsA. On arrival at the spa, we were given a foot bowl and warm water to wash our feet in, on doing so the owner checked our feet for anything that would be dangerous to the fish or general public.

On examination, he found we had verrucas!! We couldn't have the therapy but we held our treatment over until I came there again which was in July 2011. The same procedure was followed and this time everything was ok. I nervously went to my tank and gingerly put my feet in the water. Straight away the little fishes "latched" on!! It was BLISS! They were so gentle and it was so relaxing, 10 minutes was not enough.

The only downside was that the platform was raised and getting on and off was a bit difficult and sitting with your legs dangling with no full back support was uncomfortable BUT it was wonderful and my feet felt and looked so much better. I came away happy which felt very good nearly a week later. I would highly recommend this spa to any Psoriasis sufferer, the only thing to make sure is that you don't have open lesions when you go as they would not allow you in.

Yours PC

Note from editor: See page 3 for article about the health protection agency findings.

Dear PAPAA,

Once again, another night of no sleep and plenty of itching; my psoriasis is totally out of control and nothing works any more. Off to work looking like a zombie again but not before the same old ritual of plastering myself in moisturiser.

I have lived with psoriasis for over a quarter of a century and I don't mean just on the elbows, I mean head-to-toe. And I don't mind telling you that I'm sick to death of being the victim. Doctors never give psoriasis high priority as it is not life-threatening, so much so that my local hospital's dermatology ward has over the years been cut from 30 beds down to 15 beds and depending on how many woman are on the ward there are at most only four beds available for men. Because I never had any help in learning to cope with the condition even now at the age of forty two I still hide my skin from the rest of the world because when I was a boy I was always made to feel dirty. I'm tired of taking my holidays in hospital as I can't afford to lose the wages. I'm tired of paying for prescriptions, I dread to think how much psoriasis has cost me. I'm tired of covering up in the summer. I'm tired of creams. I'm tired of trying to find out what helps I can get as my boss has little understanding or sympathy towards my problem. Sometimes I just want to lie in bed and never get up I guess I'm just tired with it all.

Yours DJ

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

Q: ***Is body piercing safe with psoriasis?***

A: A common trigger for psoriasis is injury to the skin (Koebner's phenomenon), where a psoriatic lesion develops in the area damaged. If you want to have body piercings make sure you discuss this with your doctor or healthcare provider, in order to get the facts about how these procedures may affect you.

Q: ***How common is nail involvement in psoriatic arthritis and what is onycholysis?***

A: Nail psoriasis affects 80-90% of people who have psoriatic arthritis, which includes pitting, ridging and onycholysis, which is a severe form of the psoriatic nail dystrophy in which there is thickening, splitting of the nail into layers and crumbling of the edge.

Q: ***What are sausage digits in arthritis?***

A: This is the term used when an entire toe or finger can become swollen or inflamed the medical term for this is dactylitis.

Q: ***Can you get carpal tunnel syndrome with psoriasis?***

A: Carpal tunnel syndrome is fairly common; symptoms include numbness, tingling and a burning pain in the hand. The symptoms start off by occurring at night, often waking the patient; later they may also be experienced during the day and in some cases be so severe they can interfere with the normal use of the hand. If you have symptoms of carpal tunnel, talk to your doctor to find out what is causing your symptoms.

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

Log onto the PAPAA Facebook page and read what other people are talking about. You can access the PAPAA page by clicking the link from our website via the articles link on the home page.

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

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

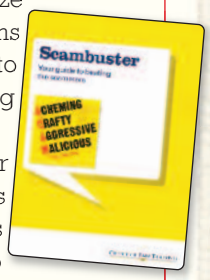
We also have a Twitter page linked to our Facebook page so if you prefer the micro-blogging site then you can follow us by clicking the link which is also located on our article section.

Follow us on Facebook

Marketplace

We're all vulnerable to buying products which appear to be bargains or sound too good to be true. To help you avoid such problems The Office of Fair Trading (OFT) has a range of useful booklets, which will help you to spot scams, fakes and cheats.

Scambuster is a 32-page booklet covering a variety of potential cons including miracle cures, prize draws and junk mail. The booklet contains examples of real scams, who to contact to report a scam and how to avoid being conned.



Although not always a scam, door-to-door sales can be as tempting as many of the cons mentioned in *Scambuster*. One example is buying mobility aids from salespeople who come into your home. This is covered by another booklet from the OFT is called *Buying on the doorstep* it aims to help you to avoid the pitfalls of buying mobility aids such as wheelchairs, stairs lifts and bath aids in these circumstances. The booklet advises on your rights following a sale, including the right to cancel within seven days, which applies if you spend more than £35 with a trader in your home or on your doorstep.

For a free copy of: *Scambuster: your guide to beating the scammers* or *Buying on the doorstep* contact the Office of Fair Trading on 0800 389 3158 or visit www.oft.gov.uk

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If you are looking to buy some gadgets to make life easier you may be interested in the following online resources which a member has brought to our attention.

OT Stores™ is a company based in Malvern, Worcestershire, which works closely with healthcare professionals and members of the public on a daily basis to provide a comprehensive range of products, all designed to make life easier. The website sells healthcare aids, disability aids and mobility aids backed by support from qualified in-house occupational therapists.

OTS Ltd, PO Box 234, Malvern WR14 1QB, United Kingdom Tel: 0845 260 7061
Email: info@otstores.co.uk www.otstores.co.uk

If you are struggling to make choices or need some impartial advice, the Disabled Living Foundation (DLF) might prove a good place to start.

DLF is one of the UK's leading health charities, and provides expert and impartial advice to people of all ages, helping them find equipment to assist in the everyday tasks essential to independent living.

Disabled Living Foundation, 380-384 Harrow Road, London W9 2HU
Tel: 020 7289 6111 Email: info@dlf.org.uk

Psoriasis Shop

www.psoriasis-shop.org

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

Getting the best prices online:

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

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

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

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

Are you on Facebook or Twitter?

If so why not help us to develop our profile?

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

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