Skin'n'Bones connection

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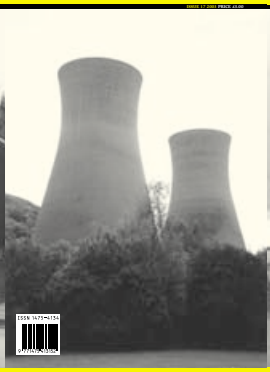

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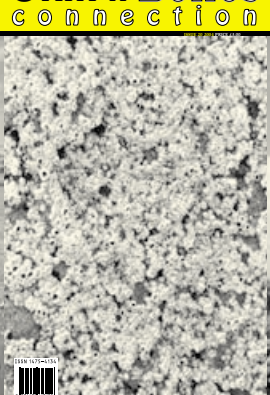

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The Psoriatic Arthropathy Alliance is a registered national charity dedicated to raising awareness and helping people with psoriatic arthritis and its associated skin disorder known as psoriasis.

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Changing times

EDITORIAL

Have you ever felt that the Internet is a confusing place? Or that the information is too good to be true? In a recent search via the Google search engine it returned 14,000,600 references for psoriasis and 1,040,000 for psoriatic arthritis. If you misspell a word, Google will offer a 'did you mean?' option, but looking at the misspelled results can be a revelation. For instance spell psoriasis without the 'a' and you get 14,500 references. Now this could be due to mistakes in proof reading or a clever marketing ploy.

The problem with the Internet is how to understand the relevance and accuracies of data and any agendas that are driving the information. For example there are many sites which at first glance appear to be independent, but on closer examination are produced as part of a marketing public relations activity in order to influence viewers towards a particular treatment or course of action.

In the UK the marketing of medicine and promotion to the general public is strictly regulated, but introduce the internet into the equation and we all have access to everything. What sometimes appear to be innocuous links to a site sponsor can immediately provide information and promotion of treatments that would be illegal in the UK under normal circumstances.

Although, there is little legislation over what is placed or can be accessed on the Internet, there are a band of individuals trying to offer some insight and tips. An interesting site is Quackwatch (www.quackwatch.org) It is based in the USA and was launched in 1996 and it's purpose is to combat health-related frauds, myths, fads, fallacies, and misconduct. The site is run as a not-for-profit site funded by small donations.

The role of the internet is going to become an increasing part of our daily life and access to trusted information will become harder to find. The PAA is in the process of redeveloping the organisation and in particular the delivery of information via the website. As part of this process we will be asking for views and opinions, the intention is to be inclusive, non-biased and not exclusive. Unlike many organisations the PAA will continue to provide information and services via all media this will include printed media, internet and telephone support.

We intend to gauge the views of people registered with the PAA about new media, communication and information delivery. We are currently running a pilot survey and will be mailing final surveys out soon. The response will be anonymous and no identification will made to those who take part, as we believe that this will provide a useful insight and honest opinions.

David Chandler

Front cover picture:
Previous editions issues of Skin 'n' Bones Connection, the first issue was produced in October 1993 with only 150 copies printed and circulated. *(see page 17)*

New treatment guidance issued by NICE

NHS National Institute for Health and Clinical Excellence

In July, the National Institute for Health and Clinical Excellence (NICE) issued guidance for the use of the targeted biological therapies, etanercept (Enbrel) and efalizumab (Raptiva), to treat adult patients with severe plaque psoriasis. and the use of etanercept (Enbrel) and infliximab (Remicade) to treat adult patients with psoriatic arthritis.

What has NICE said about etanercept and efalizumab for psoriasis?

Etanercept should be offered as an option for treating adults with severe plaque psoriasis when:

- other treatments haven't worked (for example, drugs given by injection or orally, that is, by mouth), or
- these other treatments cause a reaction which means that the person shouldn't continue taking them, or
- the person has another condition or uses another medicine that means they should not take these other treatments.

If the person's psoriasis has not shown a measured response to etanercept after 12 weeks, the treatment should be stopped.

Efalizumab should be offered as an option for treating adults with severe plaque psoriasis if:

- the person meets the criteria in the three bullets above, and
- etanercept hasn't worked, or
- etanercept causes a reaction which means that the person shouldn't continue taking it, or
- the person has a condition or takes another medicine that means they should not take etanercept.

Further treatment with efalizumab is not recommended unless the person's psoriasis has shown a measured response at 12 weeks.

What has NICE said about etanercept and infliximab for psoriatic arthritis?

Etanercept should be offered as an option for treating adults with psoriatic arthritis when:

- the person has arthritis with three or more tender joints and three or more swollen joints
- at least two other disease-modifying anti-rheumatic drugs (DMARDs), given on their own or together, haven't worked.

Infliximab should be offered as an option for treating adults with psoriatic arthritis if:

- the person meets the criteria in the two bullets above, and
- etanercept causes a reaction which means that the person shouldn't continue taking it, or
- the person has a condition or is taking another medicine that means they should not take etanercept, or
- the person has major difficulty injecting themselves.

If the person's psoriatic arthritis has not shown a measured response at 12 weeks, their treatment with etanercept or infliximab should be stopped.

New Single Technology Appraisals (STA) announced

Following the above published guidance NICE has announced Single Technology Appraisals (STA) for adalimumab (Humira) and leflunomide (Arava) for psoriatic arthritis and infliximab (Remicade) for psoriasis. This new process is designed specifically to appraise single technologies, with limited indications. The process is suitable for all single technology appraisals, including new technologies, new indications for existing technologies and reviews of existing guidance. However, the decision as to which technologies use the process will be made at the topic selection stage. Key stages of the existing appraisal process have been adapted to reflect the requirements and reduced complexity of a single technology appraisal.

Copies of the guidance, appraisals and single technology appraisals including documents for patients, carers and the public are available to view or download from the ***NICE*** website: www.nice.org.uk

NHS Direct online (www.nhsdirect.nhs.uk) may also be a good starting point for finding out more. Your local Patient Advice and Liaison Service (PALS) may also be able to give you further advice and support.

Skin'n'Bones Connection

About NICE

NICE produces advice (guidance) for the NHS about preventing, diagnosing and treating different medical conditions. The guidance is written by independent experts including healthcare professionals and people representing patients and carers. They consider all the research on the disease or treatment, talk to people affected by it, and consider the costs involved. Staff working in the NHS are expected to follow this guidance.

To find out more about NICE, its work and how it reaches decisions, see www.nice.org.uk/aboutguidance

What does this mean for me?

When NICE recommends a treatment, the NHS must ensure it is available to those people it could help, normally within 3 months of the guidance being issued. So, if you have severe psoriatic arthritis or psoriasis and your doctor thinks that etanercept, infliximab or efalizumab is the right treatment for you, you should be able to have the treatment on the NHS. Please see www.nice.org.uk/aboutguidance if you appear to be eligible for the treatment but it is not available.

EXERCISE AND WATER CAN BE FUN HONEST!!!

Anyone who has arthritis knows how difficult it is to do the most simple things in life, whether it be threading a needle, undoing a jam jar, gardening, or just unlocking a door.

The thought of exercise when you are in pain is no incentive to get fit and healthy, with the additional benefits of a rich, healthy glow to one's complexion. However, Aqua exercise just may be a fun way to meet friends and get fit too!!

The benefits of hydrotherapy, and water exercise have been known for years, but applying this thought to one's situation may have been somewhat distant until now.

The buoyancy of water reduces the pressure on joints, making it possible for people with arthritis and other painful injuries to exercise with a greater range of motion, but reducing the impact normal exercise on dry land would have.

Most leisure centres with pools will have aqua aerobic classes during the day or in the evening – just sign up on your own or with a friend, or family member and have a try.

You feel positive because you are trying to help yourself. You can do as much or as little as you feel able to in the classes because nobody notices as they are all too busy trying to work out how to do the exercises demonstrated on dry land by their teacher!!

If you feel self-conscious, especially if you have psoriasis too, be brave, as you find that most people that go to the evening ones are going for personal rehabilitation reasons too, whether they have weight problems, getting fit after injury or generally. It may not be as disheartening as you think, but open up a new area of fun. Again most sessions in the evening are single sex sessions.

If you have lost mobility, feel stiff and want to get back into participating in life more, you could always discuss the possibility of having some physio hydrotherapy sessions at your hospital if they have a hydrotherapy pool. Physiotherapists can get you moving again by slowly mobilizing your body in a small warm water pool for a few sessions. Worth discussing with your doctor.

For the more reserved, there is always the possibility of looking into your own hot tub in the garden. They come in all shapes and sizes, with various strengths of massage options. They may be expensive, but if you are in pain, you are considering these as a hydrotherapy benefit and not for pure indulgent pleasure – so don't feel guilty. It never hurts to have a look and enquire about all the options available to you. Why not even try a free wet test from a reputable dealer to see how these can benefit your wellbeing.

Julie Chandler

Swimfit

If you go to the gym you have an instructor setting you a programme, tracking your progress and providing advice. Swimfit offers you the same service for your visits to the pool. If you want to use swimming as a way of improving your fitness, Swimfit will guide you every step of the way.

For just £9.99 a year, Swimfit members of all ages and abilities are enjoying access to these fantastic resources:

- Over 30 easy-to-follow training programmes for swimmers of all abilities
- A personal online logbook, designed to keep track of your progress
- Performance analysis. An interactive facility for members to monitor their overall distances, average speed per stroke and the calories they've burned
- Take on Planet Swimfit. Set yourself a fun challenge by trying to swim the length of the River Nile or from the Earth to the Moon in just two of the many enjoyable endurance tests!

SWIMFIT MEMBERS ALSO

- Receive a free Swimfit cap and goggles*
- Subscribe to Swimming magazine for just £20 a year
- Receive e-mails providing advice on maintaining a healthy lifestyle both in and out of the pool
- Benefit from exclusive discounts on Swimzone training packs developed by double Olympic medallist Nick Gillingham MBE
- Receive a 10% discount on all purchases from the ASA

**Please note that international subscribers are not eligible to receive a free cap and goggles.*

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Managing Arthritis Pain

Suffering from chronic pain? Seek professional help

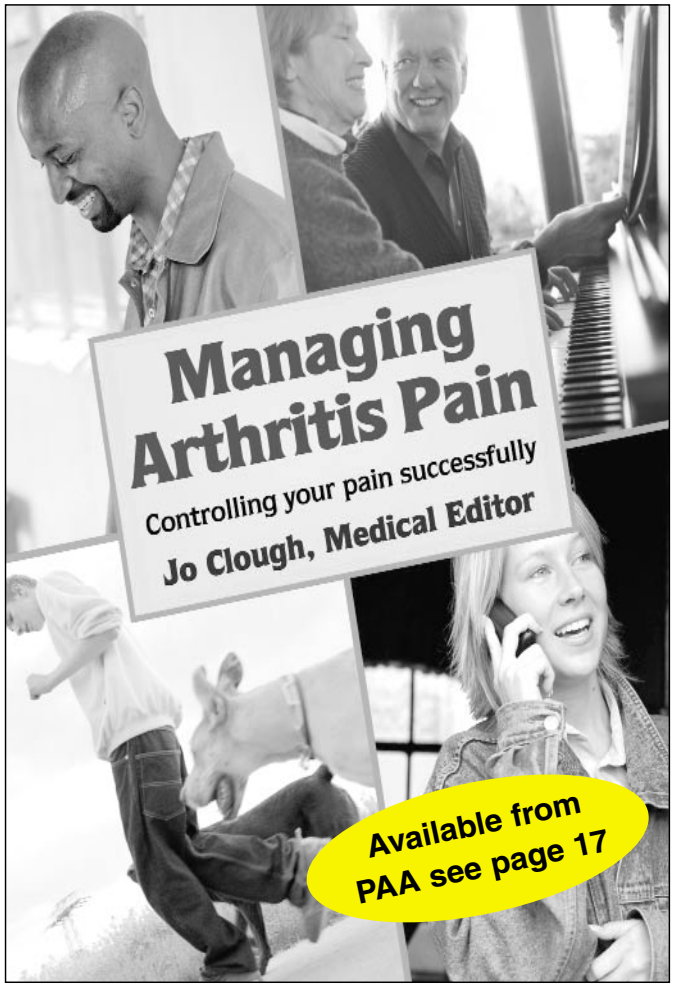
When someone suffers an acute attack of pain such as that resulting from a broken bone, an ear infection or kidney stones, for example, they are understandably expected to consult a doctor. However, when a person experiences chronic, long-standing pain arising from a condition such as arthritis, they are far less likely to seek medical help.

But pain is not necessarily something you 'just have to live with'. A doctor should properly diagnose any type of continuous pain, and together you should be able to devise a pain-management plan to treat the pain and prevent it worsening. If you continue to battle through without proper treatment the pain can affect your whole body. Muscles can weaken, posture can be affected, your immune system may suffer and you could become depressed.

There are a number of potential strategies to relieve pain. Some strategies are medical and others involve alternative approaches. Something as simple as a daily stretching routine or applying a bag of frozen peas could alleviate some pain. It is also necessary to address the mental aspect of pain management, which can be the toughest task of all. However, keeping your spirits up, avoiding negativity and focusing on things other than the pain can be greatly beneficial to the way you feel. All pain is unique to the sufferer, and this book explores a range of methods that you can employ to help you lead a normal life.

Managing Arthritis Pain outlines a comprehensive series of strategies to combat and control the many different types and severities of chronic pain.
This book give you:

- Detailed information on the different causes and forms of arthritis pain
- Advice about diagnosing your pain and obtaining the appropriate care
- Comprehensive summaries of effective pain medications
- Information on other clinical treatments such as pumps, implants, neurostimulation and surgery



- An objective, no-nonsense guide to food supplements, natural remedies and alternative therapies
- Suggestions for useful self-help pain relief including massage, exercise, hot and cold treatments and relaxation techniques

Written in a very straightforward and accessible way, this book allows you to choose the approaches that are most appropriate for you and your type of pain.

About the medical editor

Dr Jo Clough trained as an anaesthetist, specialising in pain management. She is a Fellow of the Royal College of Paediatrics and Child Health and a member of the Royal College of Physicians. She worked as a paediatric physician specialising in asthma and allergic diseases and was a senior lecturer at the University of Southampton. She now works as a Medical Adviser and is the author of Allergies at your Fingertips (Class Publishing).

Making sure you take oral methotrexate safely

NHS National Patient Safety Agency

Oral methotrexate is a well-established and effective medicine that can help treat many conditions. Over 50,000 patients are given oral methotrexate in the NHS each year and most people receiving it are greatly helped by it and suffer few, if any, problems. However, the NPSA has been told that some patients have been harmed because the medicine was not taken correctly.

What is oral methotrexate?

Oral methotrexate was first used to treat cancer. It is now known that low doses of the medicine can also help several joint, skin and bowel conditions.

It is used to treat some types of rheumatic disease such as rheumatoid arthritis, psoriatic arthritis and juvenile idiopathic arthritis, as well as severe psoriasis, and bowel diseases such as Crohn's disease. It is also used in some other conditions where the body's natural defence system is overactive.

What are the risks?

The NPSA has found that, over ten years, 25 patients in England died and 26 suffered serious harm because they did not take oral methotrexate correctly or were not monitored properly by the healthcare staff looking after them. However, most people who take oral methotrexate do not have any problems.

It is important that you are aware that oral methotrexate is a powerful medicine and that it should be taken carefully. You should be told about the possible side effects and what you should do if you experience any of them. Your doctor, nurse or pharmacist will give you information about the medicine and will tell you how to avoid having problems whilst taking it.

How should I take oral methotrexate?

You must only take oral methotrexate once a week, on the same day each week. You will take it at home and so you must be clear about how and when you should take it. You should also have regular check-ups to make sure the medicine is working correctly.

How can I make sure I am taking oral methotrexate properly?

You should:

- read and keep the instructions that come with your tablets so that you can refer back to them;
- understand how many tablets to take;
- not confuse oral methotrexate with other medication you take more frequently;
- know what the warning signs are that the medicine is not working properly;
- be monitored properly by your doctor, nurse and/or pharmacist.

What information should I receive?

You should discuss your treatment with your doctor, nurse or pharmacist before you start taking the medicine. They should give you a leaflet containing detailed information about oral methotrexate, which you should read. You should also be given a booklet that will help you and your doctor, nurse and pharmacist monitor the amount of oral methotrexate you take. This will also be used to record the results of your blood tests.

You should be given the leaflet and booklet before you start taking oral methotrexate and you should take this information with you each time you go to see your doctor, nurse or pharmacist.

The doctor or nurse treating you may give you further information that explains your particular condition and treatment in more detail. You should read all the information you receive.

What should I do if I am concerned about taking oral methotrexate?

You should talk to your hospital doctor, GP, nurse or pharmacist if you have any concerns. However, it is important that you do not stop taking the medicine before speaking to them.

Patient briefing issued by National Patient Safety Agency (1/6/06)

Further information can be obtained by visiting: www.npsa.nhs.uk


NHS National Patient Safety Agency

Patient briefing

Alert

1 June 2006

Making sure you take oral methotrexate safely

what patients *really* want

The International Alliance of Patients' Organizations (IAPO) recently released the results of a new survey on perceptions of healthcare among patients' organization members in 10 EU Member States, Canada and Nigeria demonstrate strongly shared views on the needs and concerns of members related to currently administered healthcare and signal a need for a shift to a more patient-centred approach. The findings were presented by IAPO at the international conference "Geneva Forum: Towards global access to health`.

IAPO's Policy and External Affairs Director Jo Harkness who presented the survey results in Geneva said: "Patient-centred healthcare, whereby systems are specifically designed to address the needs and preferences of patients, may be the most cost-effective and appropriate way to improve health outcomes for patients around the world. Concerted actions to develop and implement measures that reflect this approach are crucial. IAPO calls for the support and collaboration of government, healthcare policy decision makers, industry and physicians' organisations to take a pro-active stance".

The study randomly polled 1200 members of patients' organisations in 12 countries. It identified three recurring themes in the findings across the different regions that illustrate shared concerns related to the accessibility of individualised treatment and healthcare information.

Timely access to the best medicines and information is one of the primary concerns of patients and patients' organizations. 98% of respondents agree that "because timing is so important in the prevention of disease, access to the most effective medicines when you need them most is essential". The same percentage agrees on the need for greater access to accurate, relevant and comprehensive information to help patients and healthcare providers make informed decisions.

The findings also show that 95% of members of patients' organisations demand a right to participate as partners in making healthcare decisions which affect their lives. The same proportion of members agrees that patients have a fundamental right to patient-centred healthcare that respects their individual needs, preferences and values. They think that unburdening bureaucratic restrictions on physicians would allow for a stronger physician patient relationship and result in the best treatment for each individual. 89% of them argue that assuming a "one size fits all" attitude to medicines is wrong, since patients react differently to medications depending on many factors, including their health status, age, and physical make up - doctors are trained to assess all these factors and make the best decision for each individual patient.

A third and increasingly important trend the study indicates is a strong belief in increasing the involvement of patients as partners in shaping healthcare policy decisions that affect their lives. Whether this occurs through direct involvement in government-led legislative procedures and consultations or through third parties such as patients' organisations, the vast majority support the engagement of patients in healthcare policy decision-making to ensure that policies reflect patient and caregiver needs. In fact, 95% of members believe that governments should more actively take into account the views of doctor and patient organisations - including 62% who firmly stand on this position.

"What these findings demonstrate is the pressing need to align local healthcare systems better with patient needs and expectations to the benefit of both, leading to the most cost-effective disease prevention and care for each unique person," concluded Jo Harkness.

About the study:

A summary of the study on perceptions of healthcare among patient organizations is available on the IAPO website (www.patientsorganizations.org).

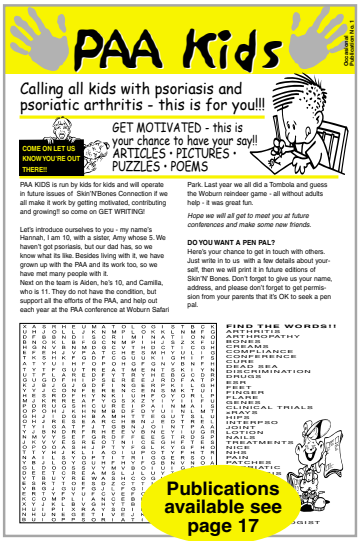
The study was undertaken by Consensus Research Group (www.consensus-research.com) in April and May 2006 among 1200 members of patients' organizations in 12 countries and supported by Pfizer.

Study participants; UK, Germany, France, Hungary, Austria, Czech Republic, Italy, Spain, Belgium, Sweden, Canada, Nigeria

International Alliance of Patients' Organizations
A global voice for patients

PAA Kids

Calling all kids!


PAA Kids

Calling all kids with psoriasis and psoriatic arthritis - this is for you!!!

GET MOTIVATED - this is your chance to have your say!! ARTICLES · PICTURES · PUZZLES · POEMS

COME ON LET US KNOW YOU'RE OUT THERE!!

PAA KIDS is run by kids for kids and will operate in future issues of: Skin'N'Bones Connection if we all make it work by getting motivated, contributing and growing!! so come on GET WRITING!

Let's introduce ourselves to you - my name's Hannah, I am 10, with a sister. Amy whose 5. We haven't got psoriasis, but our dad has, so we know what its like. Besides living with it, we have grown up with the PAA and its work too, so we have met many people with it.
Next on the team is Aiden, he's 10, and Camilla, who is 11. They do not have the condition, but support all the efforts of the PAA, and help out each year at the PAA conference at Woburn Safari Park. Last year we all did a Tombola and guess the Woburn reindeer game - all without adults help - it was great fun.

Hope we will all get to meet you at future conferences and make some new friends.

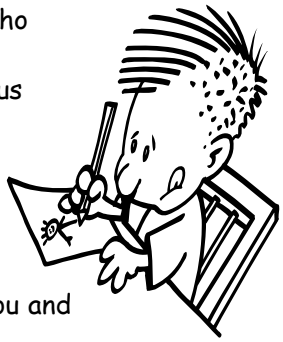
DO YOU WANT A PEN PAL?
Here's your chance to get in touch with others. Just write in to us with a few details about yourself, then we will print it in future editions of Skin'N' Bones. Don't forget to give us your name, address, and please don't forget to get permission from your parents that it's OK to seek a pen pal.

FIND THE WORDS!!
ARTHRITIS
ARTHROPATHY
CORTS
CREAMS
COMPLIANCE
CONFERENCE
CURE
DEAD SEA
DISCRIMINATION
DRUGS
ESR
FEET
FINGER
GENE
GENES
CLINICAL TRIALS
HOPE
HIPS
INTERPSO
JOINTS
LOTION
NAILS
TREATMENTS
NICE
NHS
PAIN
PATCHES
PSORIATIC
PSORIASIS
RHEUMATOLOGIST

Publications available see page 17

WE NEED YOU

We are looking for a PAA KIDS council, A group of people who can improve the lives of kids and their families, who have psoriasis and/or psoriatic arthritis, making it better for all us kids.

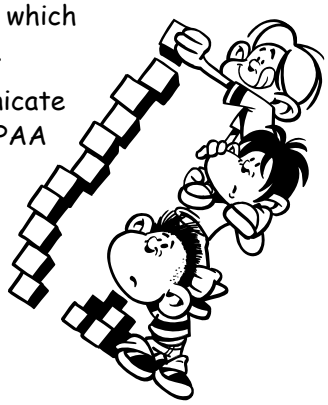


You would be able to view your opinions, and give us great ideas.

- We will have meetings
- We will discuss future plans that will make it better for you and other PAA KIDS!
- How we present our views and ideas.
- Kids Packs
- Leaflets, future magazines and journals.
- Good treatment and bad
- Good doctors (referrals)
- How we get started
- How we communicate with other PAA KIDS

For those of you who cannot make the meetings we want to go VIRTUAL, which means you can all join in and have your say and make a difference anyway.

We want a helpful, fun, friendly environment which we can use to communicate and discuss things and plans. We want purpose and meaning to the group PAA KIDS. So if you want to make a difference join us in our Victory march!



If you want to join us or to be kept informed just write in with your name, address, telephone number, e-mail address, and any ideas you have!!!

Hannah Chandler, PAA Kids, Psoriatic Arthropathy Alliance,
PO Box 111, St.Albans, Herts, AL2 3JQ. info@ThePaa.org

Rosie's Armchair Exercises

A complete body workout from the comfort of your own armchair – includes

EXERCISES AND ADVICE FOR AIR TRAVELLERS.
By Rosita Evans

Now everyone can enjoy regular exercises – thanks to fitness expert Rosita Evans' unique and effective regime.

- A complete body workout.
- All exercises performed in a sitting position
- Gently stretches and tones the muscles, keeping the joints mobile.
- Great for anyone with mobility problems who finds conventional exercising difficult.
- Hastens recovery from illness, injury or an operation.
- Medically approved.
- Includes armchAIR exercises and tips for healthier air travel.

DISCOVERY BOOKS
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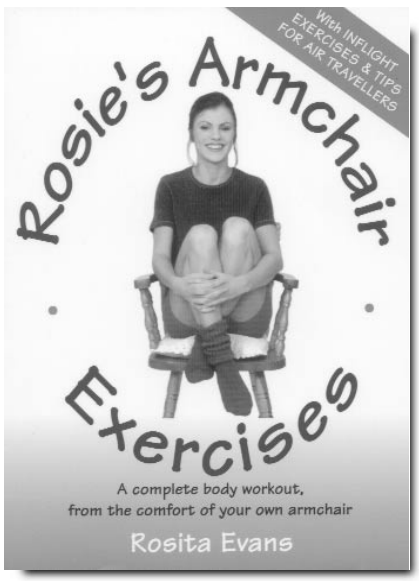


Available from PAA see Publications page 17

Letters

Dear PAA

I am 45 years old and reasonably fit and healthy and have always had beautiful skin all my life. A few years ago I started to get the odd patch on my elbows and neck of psoriasis.

In 2000 I moved to live in Spain and unfortunately from the time I arrived I had severe problems of every sort and suffered much upheaval and for my part one illness after another. Last year October 2004 I started to get patches of dry skin on my wedding ring finger and upon seeing the doctor was told it was an allergy. I noticed that 2 fingers were bent and very painful and the only thing that would help was Dead Sea Mineral Salts – I would soak them for 1 hour 2 x per day. I noticed that very rapidly the problem spread to the palm of the left hand and then it spread to the right hand. Still my doctor insisted it was an allergy and put me through endless allergy tests and made me try approximately 20 steroid etc creams all to no avail. Just before Xmas, the palms of both hands were a complete mess with dried cracked and bleeding skin, I was unable to have a bath (cool showers only), could not cook, lift anything etc. Then suddenly the whole thing exploded all over my body with pustules everywhere other than my face.

It was horrific and I saw a new doctor who diagnosed psoriasis immediately and put me on Coal Tar treatment – this brought it all under control immediately until he brought in a Harley Street dermatologist who saw me in January – she then put me on Clovate +2% acid to get the situation even better and various scalp lotions as by this time my scalp was affected.

I went through a terrible period of constantly applying lotions and creams and during this period I lost a lot of hair and my nail beds on my hands were ruined. I lost all my confidence and self-esteem and refused to go out at all.

In March of this year I just about had the situation under control with the body cleared up and the scalp much better (hair was not falling out anymore) and then I had a sudden thrombosis attack in my right knee leaving me incapacitated totally. The psoriasis flared up again but I have it back under control now and nearly gone – the reason they felt it flared up in the first place was extreme stress – unfortunately during the period I had the moderate to severe attack I was still having problems with my family in the UK and problems with the business here and so on; hence it never really stood a chance. Added to that I could not even go out to de-stress as I was so self conscious.

Now I am pleased to say that my body has cleared up completely leaving only a few scars, my hair is slowly growing back although it is weak; my scalp is much recovered. My hands are nearly back to normal although still rather pinky in colour owing to months of shedding skin etc.

I must tell you that at one point early in the year I was put on drugs for the problem but my liver count became raised (even though I was not drinking alcohol) and I had to stop the drugs.

I have read quite a lot about psoriasis even before I had this attack and never believed for one minute I would have such a problem to deal with. Now I have been through it, I am trying to ensure that I take every precaution to minimise this occurring again in the future.

Consequently I have set myself on a strict diet (we always did eat healthily), do not drink alcohol anymore (we were never heavy drinkers I hasten to add! Just a few glasses of wine), am taking many supplements and trying to make time for myself to de-stress until I can get out more.

I have read that certain dietary factors may contribute and I wondered what was your opinion on this matter- my doctor does not agree with me but I am convinced that "you are what you eat etc" – however in my case it was not anything I was eating that was the trigger – but I would be interested in your opinions – i.e. I have read you should not eat anything red – tomatoes, kidney beans, red meat etc (we only eat chicken and fish and very rarely red meat!)

The other factor is that I suffered quite bad tendonitis in one wrist joint, I was advised this was caused by the psoriasis and might need a cortisone injection. So far I have avoided this and hope that once my nails grow back this will rectify itself and all I do is put ice on the joint twice per day.

Well apologies for such a long letter gleaned about this condition.

I am particularly interest in the following

1. Do you feel there is a link to diet?
2. In your experience/research what are the main triggers?
3. Is there anything you can do once your nail beds are destroyed and while you wait for new nails to grow? The doctors say not but I wondered if there was some oil you could apply etc? I feel very self-conscious about my nails but there does not appear to be much I can do about it.
4. As far as the tendonitis is concerned some days it is so painful I can hardly lift a plate – I cannot take anti-inflammatory drugs as they will affect my blood reading as I am taking Warfarin at present for the thrombosis attack
5. Do you feel that any particular vitamins help? I take quite a few daily and drink lots of water to stay hydrated.

Yours sincerely, Mrs AB

Dear Mrs AB

Thank you for your letter, to the Psoriatic Arthropathy Alliance for reply.

In answer to your questions:

1. Regarding diet, many patients with psoriasis feel as you that their disease would be helped by a change in diet. Unfortunately there is not a lot of research to back this up other than alcohol and smoking being detrimental to psoriasis and a very high intake of fish oils being beneficial. On the other hand, certainly for individuals some people find that high sugar in their diet makes their psoriasis worse and fairly commonly people find eating tomatoes can make their psoriasis worse. There is also some evidence that patients with a combination of coeliac disease (gluten intolerance) have more severe psoriasis than those without gluten intolerance. There is a book which is written by a Dr Pegano on psoriasis entitled Healing Psoriasis, Natural Alternative, which some people have found helpful and one patient in particular had been very impressed with the results she has had following his strict dietary plan.

2. The main known triggers of psoriasis are infection such as streptococcal, sore throats, drugs such as beta blockers, lithium and anti malarials and also stress as in your case. I am sure there are other triggers and these may again be individual.

3. Psoriasis nail disease is very difficult to manage but can be helped by massaging a very potent topical steroid into the skin surrounding the nail or other topical psoriatic treatments such as calcipotriol ointment again massaged into the skin around the nail or Calcipotriol scalp application dropped onto the nail edge if this is affected. Although you describe your nail-bed as being destroyed the nail changes associated with psoriasis are not permanent and nails can grow out normally.

4. As far as your tendonitis is concerned I suggest you ask to see a rheumatologist who may be able to inject the tendons with a steroid, though again they may be reluctant to do this whilst you are on warfarin.

5. The only vitamins that may help you are fish oils such as omega 3. However, staying healthy and drinking a lot of water as you do can only be a good thing.

I hope this answers some of your questions and good luck with the management of your psoriasis.

With best wishes

Yours sincerely

Dear PAA

I would like some information about Plaque Psoriasis which I am suffering with at the moment. My Doctor has prescribed calcitriol, but it is making my skin irritated and my skin is very thin and tender, I've had psoriasis on and off for a few years, but it was not very bad. Since I had a heart operation past year it has got quite bad and all that my Doctor does is change the cream, so could you give me any advice because I had valve replacements and have had to go on Warfarin

Yours Sincerely
Mrs G B

Reply from our expert Consultant Dermatologist:

Dear Mrs G B

It is difficult to make an assessment of your skin within a letter, but I wondered firstly if the stress of the operation has caused the deterioration of your psoriasis, or whether perhaps you have been started on a drug that may have made your psoriasis worse. The calcitriol that you have been given can irritate particularly inflamed psoriasis and a period of using emollient (moisturiser only) may help. It may be worth asking your GP whether he thinks any of the tablets you have started on could make your psoriasis worse. In particular beta-blockers are known to worsen psoriasis.

Sometimes a weak steroid preparation can take the soreness out of your psoriasis for a little while, which may allow you to treat it with some of the more irritating creams. If your GP is unable to improve matters for you, it may be worth asking that you are referred to see a dermatologist.

Best wishes

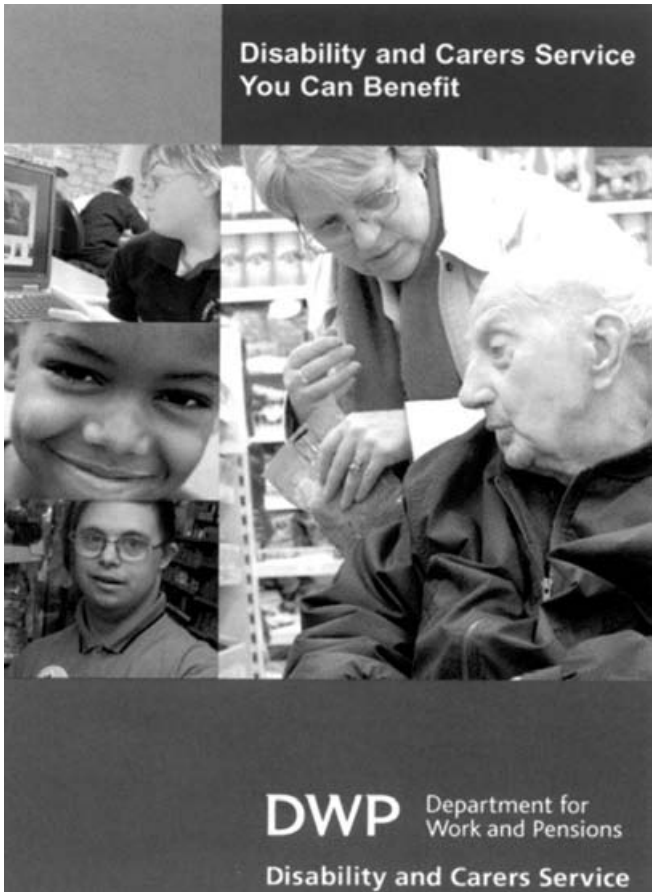
You can benefit

The Disability and Carers Service (DCS) has produced a DVD for users of British Sign Language, which explains who can get Disability Living Allowance, Attendance Allowance, Carer's Allowance and Vaccine Damage Payments.

DCS has worked closely with RNID in putting together the DVD – *You can benefit* – which also has a spoken commentary and subtitles.

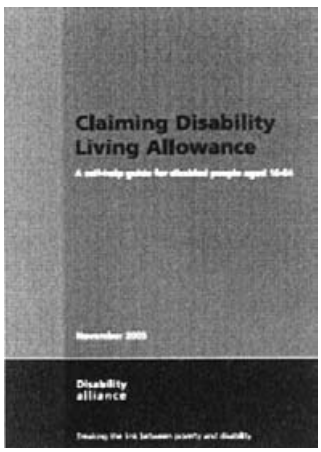
Visit **www.direct.gov.uk** to view the DVD online. Or to obtain a copy contact Kay Baddeley or Andy Minnis on 01253 338427.

Email: kay.baddeley@dwp.gsi.gov.uk



Claiming Disability Living Allowance

A self-help guide for disabled people aged 16-64



Disability Living Allowance is one of the most important benefits for disabled people. It is not means-tested, it is tax free and you can get it whether you are in work or not. To qualify you need to show you have sufficient care or mobility needs but you don't need to have a carer and you can choose what you spend it on.

Unfortunately, all too often people are put off claiming because the claim-form is long and detailed. This user-friendly guide takes you through the process of making a claim.

It explains in clear language what the qualifying conditions are and then goes through the claim-form question-by-question, providing help and suggestions on how best to present evidence.

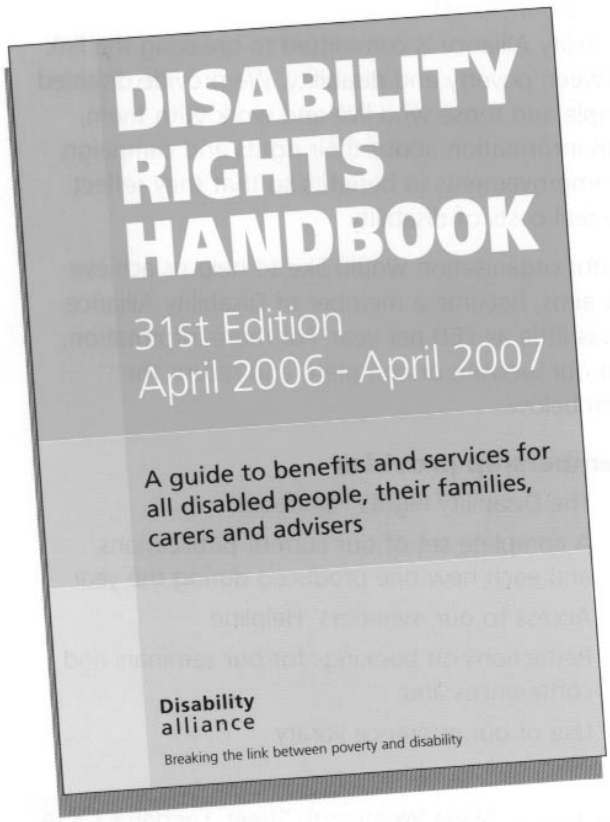
There is a chapter devoted to keeping a diary; often the best way of collecting and presenting evidence for the many disabled people whose condition fluctuates from day-to-day. Finally, the guide explains how decisions are made and what you can do if you're not happy with a decision.

New edition November 2005 - Also available on audio tape

ISBN
1-903335-32-9
978-1-903335-32-1

Price
£7.00 per copy
£3.50 for people on benefit

DISABILITY RIGHTS HANDBOOK



Benefits and tax credits

Do you have a disability or health problem? Are you clear about which benefits you can claim? If you don't know your rights, you could be missing out on hundreds of pounds each year.

Are you caring for an adult or a child with disabilities or special needs? As a carer, you may qualify for financial help. Have you thought about claiming but don't know where to start?

Do you provide services to disabled people? The people you support rely on you for accurate information. Keep up-to-date with the ever-changing benefits rules and ensure the quality of the services you provide.

Everything you need to know

The Handbook contains everything you need to know about social security benefits, tax credits and related services for disabled people. Fully updated each year, this essential reference book has helped hundreds of thousands of disabled people, their families, carers and professional advisers in the UK.

£19.00 post free
£13.50 if you're on benefit
£22.33 CD Rom

31st EDITION 2006-07 PUBLISHED MAY 2006

Includes chapters on:

- Incapacity Benefit
- Disability Living Allowance
- Attendance Allowance
- Tax credits
- Pension Credit
- Carer's Allowance
- Community Care Law
- Benefits for disabled children
- Benefits in care homes or hospital
- Industrial injuries benefits
- War pensions
- How to challenge decisions

ISBN
1-903335-30-2
978-1-903335-30-7

Price
£19.00 per copy
£13.50 for people on benefit

SUBMITTING ARTICLES

The Skin 'n' Bones Connection does accept articles, letters and press/news releases. Articles should be sent either by post or e-mail to the Managing Editor for review.

The Editorial Team cannot guarantee insertion and reserve the right to refuse inclusion without explanation of any unsolicited material. Material that is accepted may be edited and full accreditation to contributors will be clearly displayed, unless otherwise agreed. Letters to the Editor can be signed off anonymously if preferred.

Advertisements are not currently accepted. All editorial content for products, items and suppliers of such goods is based on recommendation from readers, but are not necessarily endorsed by the charity. Inclusion is for information and educational purposes. Always consult your Doctor before undertaking any new course of therapy, treatment or activity.

PO Box 111, St Albans, Herts. AL2 3JQ. E-mail: info@thepaa.org

PREPAYMENT OF NHS PRESCRIPTION CHARGES

If you have to pay for more than five prescription items in four months or 14 items in 12 months you may find it cheaper to buy a pre-payment certificate (PPC).

Details of the current prescription charge and pre-payment certificate costs are available from leaflet HC12 - *Charges and optical voucher values.*

About the PPC
You can only use the PPC for your own NHS prescriptions. The PPC will start from the date your online application, phone call or postal application is received unless you ask for a different start date. This can be up to one month earlier or one month later than the date of your on line application, phone call or the date your postal application was received. Remember to apply for a new PPC in good time, otherwise you will have to pay charges when your old PPC runs out.

If you have to pay a prescription charge while you are waiting for your PPC, you cannot get a refund unless you have an NHS receipt. The NHS receipt form is an FP57 (England). The pharmacist or dispensing doctor can only issue an FP57 at the time you pay a prescription charge; they cannot give you one later. You can claim the prescription charge(s) back, up to 3 months after paying, the FP57 tells you what to do.

Refunds of PPC fees

If you wish to claim a refund of your PPC fee please send the original certificate, proof of entitlement where possible e.g. benefit award notice or death certificate to the Prescription Pricing Authority and tell them why you want a refund. You should send your letter, proof of entitlement and the certificate to:

PPC Issue Office,
Prescription Pricing Authority,
P O Box 462,
Newcastle upon Tyne,
NE99 2DD

A full refund may be claimed for 4 or 12-month PPC fees if, within the first month, you become entitled to free prescriptions or the holder dies.

A proportional refund may be claimed for 4 or 12-month PPC fees if the holder dies after the first month.

A partial refund may be claimed for 12-month PPC fees if, within months 2-4 of the PPC, you become entitled to free prescriptions. For full details on PPC refund arrangements including the time limit for claiming a refund check leaflet HC11

Buying a PPC
The Authority's PPC Issue Office is responsible for issuing PPCs to people resident in England only, on behalf of the Department of Health.

You can buy a PPC online, by post or by phone. Ring 0845 850 0030 to buy one over the phone using your credit or debit card or buy online from the Prescription Pricing Authority website www.dh.gov.uk/mpi

From 1 April 2006, the charge for a single prescription item is £6.65, whereas a 4-month PPC will cost you £34.65 and a 12-month PPC £95.30.

If you are resident outside England the action you need to take to purchase a PPC depends upon the country you are resident in. If you are resident in:

- Scotland you can purchase a PPC from most pharmacies or dispensing doctor practices, or you can apply for a PPC by post using form EC95. The form is available from pharmacies, NHS Boards or NHS National Services Scotland Practitioner Services Division's area offices. It tells you what to do.
- Wales you can purchase a PPC using form WP95 available from pharmacies. It tells you what to do.
- Northern Ireland you can purchase a PPC from most pharmacies.

IMPORTANT - some people can get free prescriptions. You should check leaflet HC11 to see if you could get free prescriptions before buying a PPC.

GP Clinics set for Boots stores

Boots the chemist is hoping to put GP surgeries and hospital consultants in its stores across the UK.

The first consultant clinic will be tested at a Boots store in Poole, Dorset. By the end of 2006 the clinic could offer physiotherapy, healthy heart checks, orthopaedics and podiatry. They are also considering offering emergency weekend surgeries in many of their shops.

Boots will act as a landlord, renting space to the NHS. Patients referred by their GPs to consultants in orthopaedics, podiatry, physiotherapy or heart checks may be offered treatment at Boots.

The Department of Health believes that the move will help to cut waiting lists but it is likely to be criticised as a form of privatisation of NHS services.

Some large supermarkets have also expressed an interest in the scheme but a spokesperson from the BMA said they would oppose such a move saying that the sale of tobacco, alcohol and junk food would undermine the services on offer.

For further information visit
http://www.allianceboots.com

New online blue badge parking bay map launched

A new interactive online service was recently launched on www.direct.gov.uk, which will make it much easier for disabled people to find Blue Badge scheme parking bays in 64 cities across the UK.

This mapping facility is the first of its kind and will enable people to search by postcode or town/area name for designated Blue Badge parking bays, parking bays that fall on red routes in London and accessible petrol stations. The service will also outline any time restrictions or special notices that apply to individual allocated Blue Badge parking bays.

Anne McGuire, Minister for Disabled People, speaking about the launch of the service, said: "Disabled people need to be supported to live life independently in the community, at work and at leisure. That is why I am delighted that this interactive tool should really make a difference. For many disabled people who do drive or are a passenger, knowing where they will be able to park will enable them to take part in day to day activities that non-disabled people take for granted. This service will help many people a great deal."

Transport Minister Gillian Merron added: "We want everyone who is entitled to use a Blue Badge to benefit from a user-friendly and properly enforced system. Together with our recent steps to stamp out fraud, this innovative service will help badge holders, whether drivers or passengers, get more out of the scheme."

The Blue Badge scheme provides a range of parking benefits for disabled people with severe walking difficulties who travel either as drivers or as passengers. The concessions apply to on-street parking and include free use of parking meters and pay-and-display bays and are administered through local authorities.

Directgov, which brings together the widest range of public service information and services online, hosts the Blue Badge map facility in its section for disabled people which is located at www.direct.gov.uk/disability

The Blue Badge map can be viewed at:www.direct.gov.uk/bluebadgemap

Apply for a Blue Badge parking permit locally

Your local authority is responsible for issuing Blue Badge parking permits - contact them for more information. The following link will let you enter details of where you live and then take you to your local authority website where you can find out more and/or apply online. www.direct.gov.uk

Heart attack risk link

Psoriasis is an independent risk factor for heart attack, and this risk is greatest in young patients with severe psoriasis, according to Joel M. Gelfand, MD, MSCE, Assistant Professor of Dermatology, University of Pennsylvania School of Medicine, and lead author of the study that appears in *The Journal of the American Medical Association* (JAMA).

Psoriasis is associated with markers of systemic inflammation, and the immunological abnormalities that lead to the development of psoriasis suggest that these patients may be at increased risk for other diseases associated with an inflammatory state.

"Several hospital-based studies have indicated that psoriasis is associated with a higher prevalence of cardiovascular diseases, including heart attack," said Gelfand. "However, these studies did not control for any associated risk factors for heart attack."

Gelfand and colleagues conducted a perspective population-based cohort study to determine the risk of heart attack in patients with psoriasis when controlling for major cardiovascular risk factors. The study data was collected from 1988-2002 by more than 500 general practitioners in the United Kingdom who were unaware of the hypothesis being tested. The data was collected as part of the patient's electronic medical record and maintained in the General Practice Research Database.

The study population consisted of psoriasis patients aged 20-90. Among these patients, 127,139 were defined as having mild psoriasis and 3,831 patients were defined as having severe psoriasis. Adjustments were made for hypertension, diabetes, history of heart attack, hyperlipidemia (an excess of fats or lipids in the blood), age, sex, smoking, and body mass index. Each patient was matched to up to five control subjects who did not have psoriasis. These 556,995 control subjects were seen in the same practice during similar time periods.

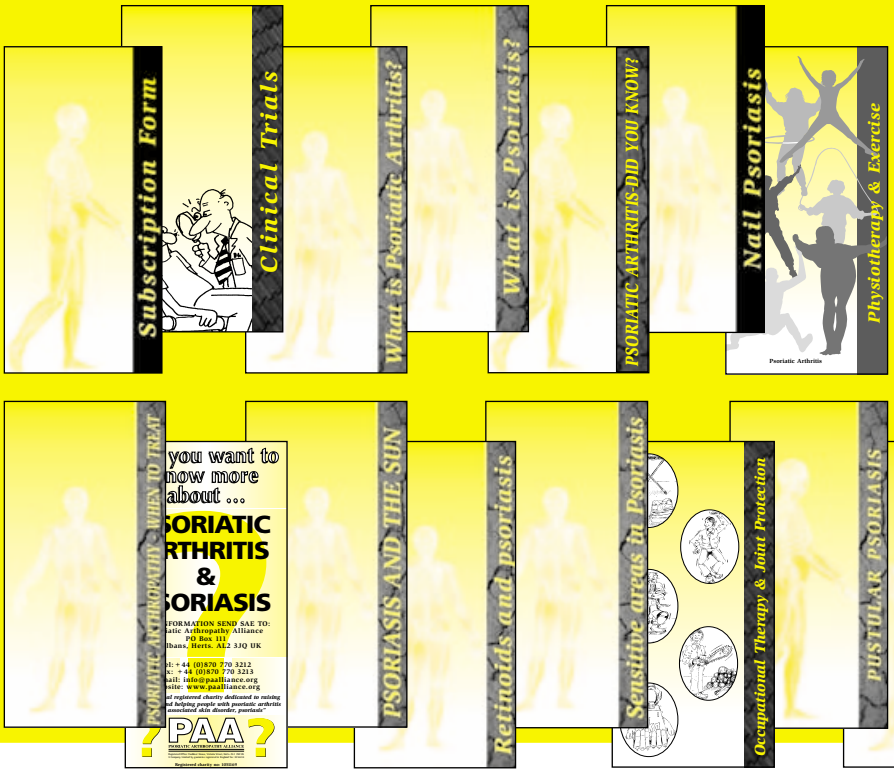
The study revealed that the incidence of heart attack was higher in patients with severe psoriasis compared with control patients. Younger patients with severe psoriasis had the highest relative risk of heart attack. For example, a 40-year-old patient with mild psoriasis had a 20 percent greater risk of having a heart attack than a patient without psoriasis; a 40-year-old patient with severe psoriasis had more than double the risk. A 60-year-old patient with severe psoriasis had a 36 percent increased risk for heart attack. The authors write that the magnitude of association between severe psoriasis and heart attack in those less than 50 years of age is similar to the magnitude of association for other major cardiac risk factors.

"Our findings are novel and therefore it is important that additional studies be performed to confirm these results and determine their therapeutic implications," write the authors. They recommend that in the meantime, as part of good medical care, patients with psoriasis should be encouraged to aggressively address their modifiable cardiovascular risk factors.

Further information can be obtained from: www.uphs.upenn.edu

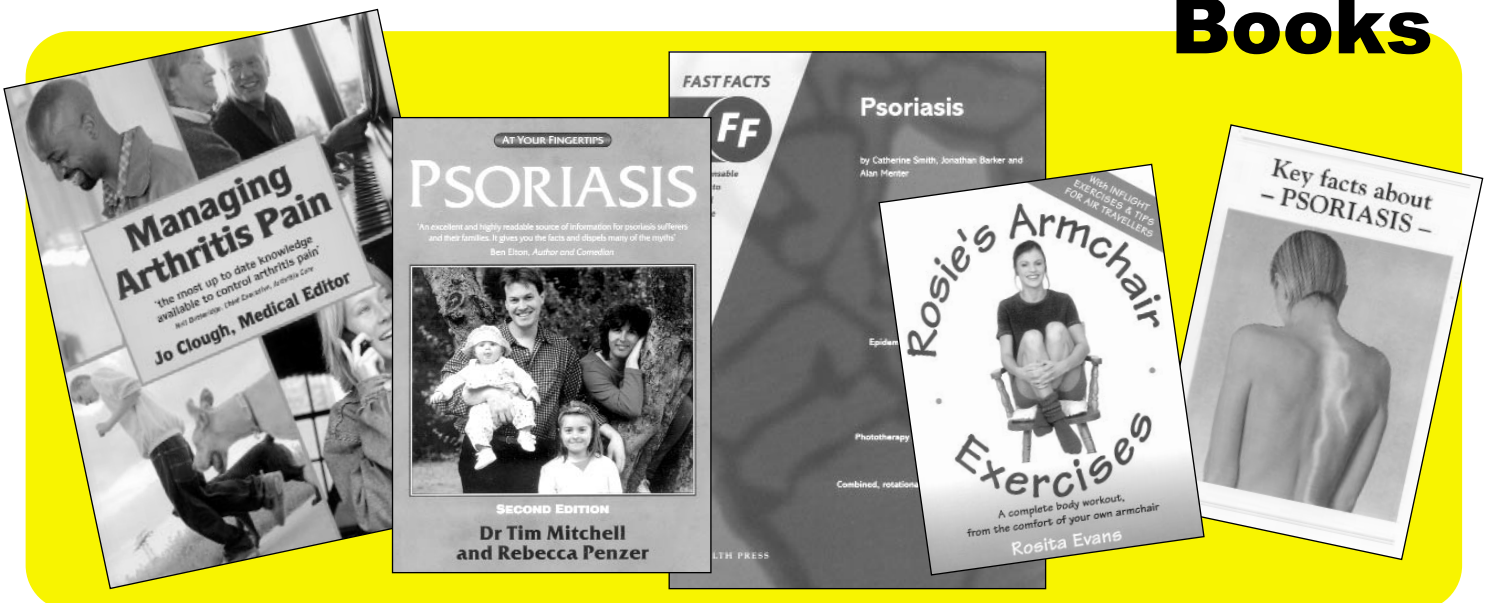
PUBLICATIONS

Information



Journals

Books



PAA Publications
order form

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All payments should be made payable to the PSORIATIC ARTHROPATHY ALLIANCE

Publication title	Issue no.	Publication Date	Unit Cost	Qty. Required	Sub total
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Skin 'n' Bones Connection	7	December 1996	50p ~~£3.00~~		
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PAA contact poster A4	-	-	Free		
Psoriatic Care Fact File- 32 fact sheets Book	2nd edition	2004	£9.50		
PAA -The Birth of a Charity A4 pamphlet	1st edition	1996	50p		
Non-PAA publications					
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Psoriasis Fast Facts	1st edition	2002	£5.50		
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Please allow 28 days for delivery. Thank you.

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PLEASE FILL IN AND RETURN TO PAA

SUBSCRIPTION FORM

Please complete the following clearly:-

SECTION 1 and SECTION 2 (optional)

SECTION 1

First Name(s) .....

Last Name .....

Title (Miss, Ms, Mrs, Mr., Other) .....

D.o.B .....

Address .....

.....

..... Postcode .....

.....

.....

Country .....

Telephone .....

Fax .....

E-mail .....

Mobile .....

I would like to be added to the PAA Register (Free) ☐

I would like to subscribe to Skin 'n' Bones Connection

UK - £12.50 (including postage and packing) ☐

Overseas: £20.00 (including Air postage and packing) ☐

I enclose my annual subscription fee of: £ .....

I would like to make a donation of: £ .....

PLEASE MAKE CHEQUES PAYABLE TO:
"PSORIATIC ARTHROPATHY ALLIANCE" Thank you.

Signed: .....

Date .....

QUESTIONNAIRE

(Completion optional and confidential)

SECTION 2

Where did you hear about the PAA? .....

.....

Occasionally we are supplied with product information and samples, would you like to receive these in the future? YES/NO

Would you be willing to enter into confidential surveys relating to psoriatic arthritis and/or psoriasis? YES/NO

How long have you had PsA? .....

How long have you had Psoriasis? .....

Areas/joints affected? .....

Medication tried (please list) .....

.....

Current Medication taken? (please list) .....

.....

Any family history of PsA or psoriasis in your family? .....

Other information:
Are there any websites or publications you think would be of interest to our readers? (please list)

.....

.....

.....

Signed .....

Date .....

All information given on this questionnaire is treated with the strictest confidence and will not be given out without the prior permission of yourself.

Thank you for your time and co-operation in the completion of this form.

What do I get if I Register?

- Opportunity to take part in patient focus group meetings
- Receive relevant mailings via PAA (such as surveys, new product information etc.)

What do I get if I subscribe?

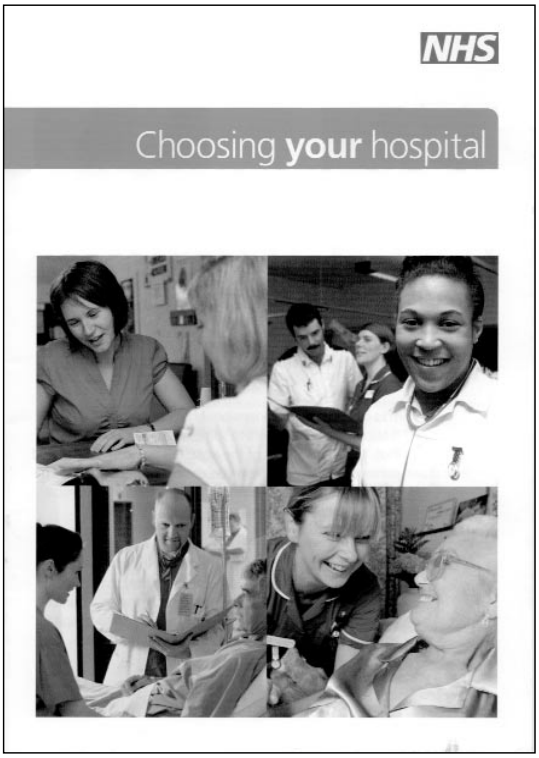
Benefits of becoming a subscriber to Skin 'n' Bones Connection are:

- Two issues per year (two back issues immediately)
- Other mailings during the year about PAA activities and events.
- Free new information leaflets when produced
- Publications list
- Automatic inclusion to the PAA Register

PLEASE RETURN TO:
Subscriptions
Psoriatic Arthropathy Alliance
PO Box 111
St Albans Hertfordshire
AL2 3JQ UK

Why give patients a choice of hospital?

Evidence points to the fact that patients want more choice over how, and where, they are treated.



Patients want more choice

According to a MORI survey commissioned by the Department for Health in November 2003, 76% of patients want to be involved in decisions about their treatment. 42% wanted to choose their appointment time and 31% wanted to choose their hospital or doctor. Giving patients more choice will make them more involved in decisions about their treatment.

More recently a YouGov poll commissioned by the Economist in April 2004 found that across all social types 66% of people wanted more choice in their healthcare.

When offered faster treatment 75% of patients in Manchester and 67% in London took the alternative choice.

50% of patients needing heart surgery have chosen an alternative hospital for faster treatment between July 2002 and June 2003.

Choice will help to drive service improvements transforming the NHS into a more responsive, patient-centred service. The new payment by results funding system and choice provide incentives for hospitals to provide more responsive services that patients want to choose.

All patients who require elective care will be offered choice of hospital with appropriate information and targeted support.

Some patients will always prefer the GP to make the decision for them. Patient choice means respecting patients who choose not to choose!

Source: Department of Health

www.dh.gov.uk

Psoriatic Patient Focus Groups (PPFG)

We are currently looking at expanding our PPFGs to become more pro-active and an inclusive part of the PAA's infrastructure.

Originally the group was solely directed at arranging small focus group meetings, to discuss various issues, such as the difficulties faced by patients when complying with their treatment regimes.

We would now like to develop this concept further, to include and develop the process of also becoming a 'virtual' group that would not necessarily need to meet and who could provide opinions or views that may include:

- *Face to face meetings*
- *Completion of surveys*
- *Media activity*
- *Organisational representation*
- *Material development and revue*
- *Other activities to be decided by you!*

By developing this concept we hope to broaden the group by making it more accessible to everyone interested in making a difference.

We want to include carers, spouses, family members and professionals within the group. It will be free to register and some activities could be anonymous.

We need you to help us develop your motivated, pro-active group, where we will listen and we will act to make care for Psoriatics and their families a whole lot brighter for the future.

If you want to be involved or have suggestions please e-mail: info@thepaa.org or write to us at: PPFG PO Box 111 St Albans Herts AL2 3JQ

GISMOS & GADGETS

Wax bath for satin soft hands and pain relief

Dipping your hands in paraffin wax not only makes your skin feel wonderfully smooth and soft but is also a treatment used in hospitals and clinics worldwide to relieve the agonising pain caused by conditions such as arthritis and tendonitis. This affordable wax spa, purpose-designed for safe home use, has exactly the same benefits and modus operandi as professional units. You simply plug it in, pour in the wax, heat to a comfortable 'hand-hot' temperature then dip hands, wrists, elbows or heels several times into the molten wax, building up a thicker layer each time. The heat stored in the wax is slowly released into the body to soothe aches and pains – and when peeled off, it painlessly removes dry or flaky skin leaving hands visibly softer. Includes a 2lb pack of re-usable paraffin wax, melting pot and 20 disposable mittens to prolong heat effect on hands and wrists. Bath measures 7½" x 13" x 10" (19 x 33 x 25cm).

109 5513 Paraffin Wax Bath £39.95

Wax bath
Available from Viva! A Scotts & Co company
Order line 0870 220 3244

Precision Nail Scissors

Toe nails may not be the most pleasant subject – but we all have them and many defy being cut by the standard scissors available in High Street chemists. Really tough nails need our award-winning Precision Nail Scissors. Made in France from hardened stainless steel. Lifetime guarantee.

■ G/2682 - £12.99

Precision scissors *Available from www.essentialsbypost.com*

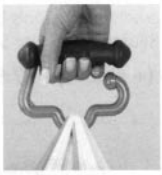
An Extra Helping Hand

Fastening bracelets, clasps or awkward watchstraps is always a struggle, when there is no one around to assist. Now help is at hand! Our elegant Bracelet Helper holds one end of your watch or bracelet, leaving your other hand free to do the fastening. A real asset for those with limited dexterity or arthritis.

109 5448 Bracelet Helper £6.95

An extra helping hand
Available from: Solutions from Renwoods www.renwoods.com

EZ Carry™



Carrying heavy carrier bags can be painful when the plastic handles cut into your hands. This brilliant device has a comfortable soft, moulded rubber grip handle and a specially designed hook from which to suspend lots of carrier bags. Bags stay together and the contents don't spill out even when put down in the car. Capable of holding up to 50lbs.

■ M/3258 - £4.99

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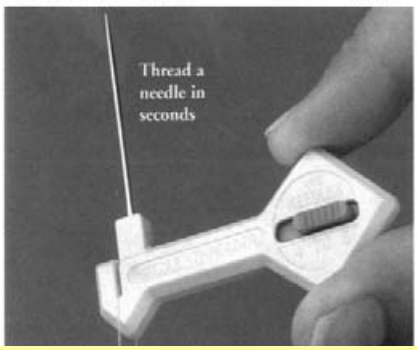
Available from www.essentialsbypost.com

Easy to Use Needle Threader!

No matter how small the eye of your needle is, our new Needle Threader will thread it for you. So simple to use, just hold the Threader in one hand, insert the needle then the thread and the job's done. A real must for every sewing kit!

107 0777 Needle Threader £6.95



Easy to use Needle Threader
Available from: Solutions from Renwoods www.renwoods.com

Twist and Spout

Sticky drinks spills will be a thing of the past with this brilliant device. Simply twist it onto any fizzy drink or water bottle and pour – what could be easier? Colour may vary.

■ M/4773 - £3.99

Twist and spout
Available from: www.giftsforthegirls.com

The PAA: Plans and philosophy

The Psoriatic Arthropathy Alliance (PAA) is continually reviewing its activities and consulting with other organisations in order to provide services and activities that will be appropriate for the changing needs of patients in the 21st century. The needs of people with psoriasis and psoriatic arthritis, is and will continue to be the thrust of all future activities the organisation delivers. These activities will be delivered in an appropriate way that is based on good evidence and input from patients, carers and healthcare professionals.

The PAA does not currently receive funds from the pharmaceutical industry or commercial sector. All activities are funded via donations, subscriptions or charitable grants. We believe that this allows us to act in a non-biased way and free from any 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 that it is beneficial to our constituent group.

We do not endorse products or make recommendations, we provide information that has been approved by healthcare professionals or has published evidence. We provide a signposting service to help people with psoriasis and psoriatic arthritis to make an informed choice and understand how to deal with their condition.