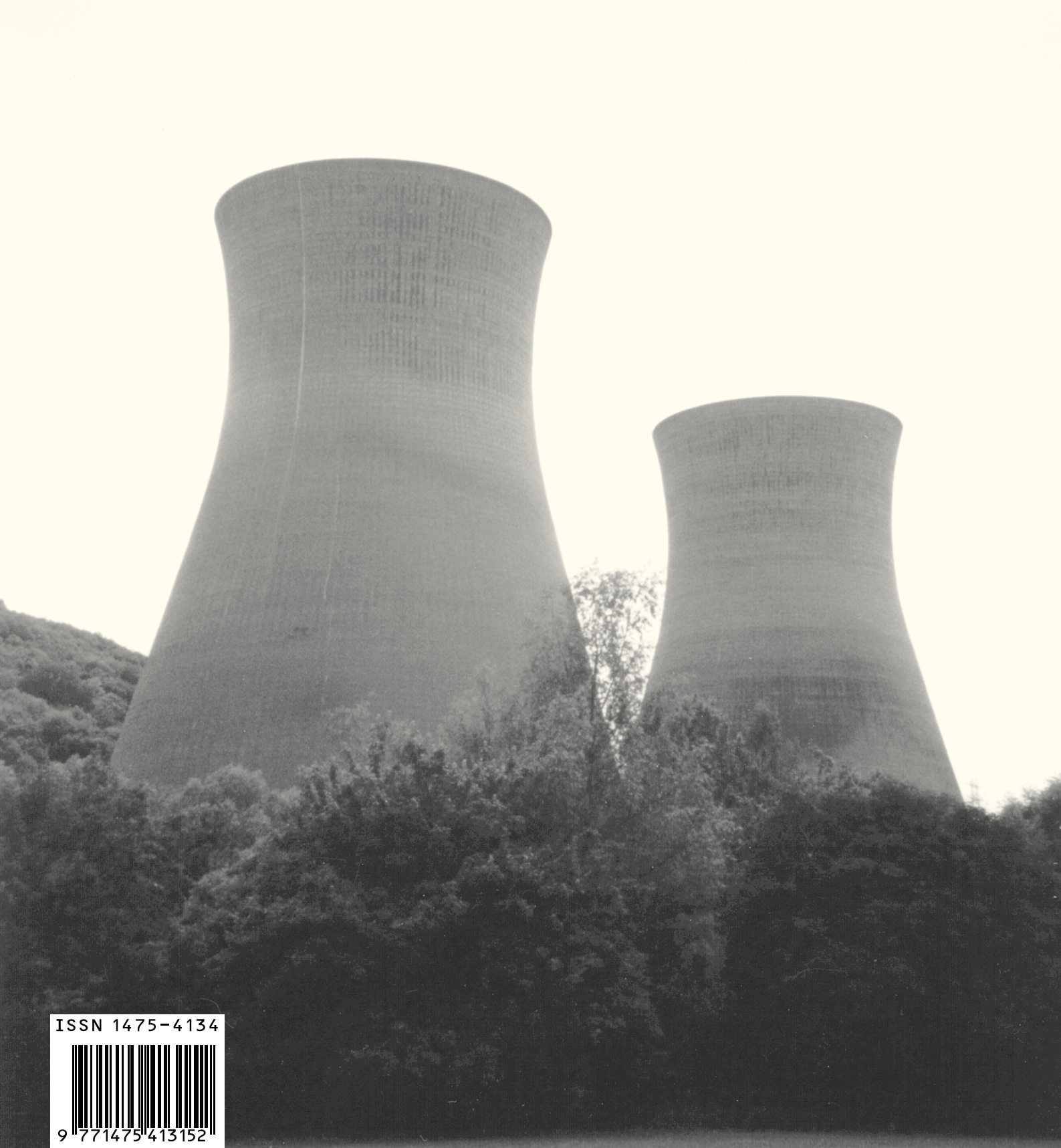


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Patient Power: What does it really mean?

EDITORIAL

I would guess that there are those who fear that there will be hoards of ill informed empowered people running amuck through NHS corridors with reams of printouts from internet sites demanding the latest most expensive unlicensed products for diseases that they do not have.

Or is it a process in which the patient is no longer treated like a specimen, that a 'Sir Lancelot Sprat'* type character can reel out in front of bemused medical students in order to prove that a little knowledge is a dangerous thing, particularly if it in the hands of the patients.

There has been much discussion and now positive steps taken for an inclusive patient centred service, the voice of the patient is becoming more and more important as the Commission for Patient and Public Involvement in Health is now signalling that there will be a shift in the balance of power in favour of patients' views.

The establishment of the new commission coincides with the new legislation that has just come into effect. Under section 11 of the new Health and Social Care Act 2001 the NHS now has a duty to involve and consult patients and the public in service planning and operation, and the development of proposals for change.

As patients we now have a 'foot in the door' and it is our duty to support the proposals and take our rightful place in the process of change. There may still be 'Sir Lancelot Sprats' striding round the NHS but the change is coming and slowly patients will be heard.

**Character played by actor James Robertson-Justice (1905-1975) in a film called Doctor in the House based on the semi satirical novels by Dr Richard Gordon*

My view of Psoriasis

When I first knew my dad had Psoriasis I was really upset. I couldn't do the things that we could do before, like swimming. Now I think having Psoriasis is not a good thing to have. As long as he feels OK I'm fine. I try to understand how he feels about having it. I want to make sure that he is alright all the time. As long as he sticks to the cream he's alright.

By Hannah Chandler
Age 8



Hannah and Friends at Woburn 2002. From Left: Hannah, Aidan, Camilla, Back: Thomas

PSORIATIC ARTHRITIS - *When to Treat*

Why do many sufferers from psoriatic arthritis (PA) not receive optimal treatment and continue to be told by general practitioners and rheumatologists that there is little that can be done for them at the present time? This seemingly negative attitude causes frustration and distress to the sufferers and their families. Much research has gone into discovering the nature of the disease and into finding effective treatments but this work has yet to be translated into universal access to the best treatment in the national health service.

The answer to this dilemma lies both in the nature of psoriatic arthritis and the types of drugs available. Except in its severest form, which occurs in less than 10% of sufferers. Psoriatic arthritis is a very much milder disease than other common forms of arthritis such as rheumatoid arthritis or ankylosing spondylitis. Indeed it does not cause as much disability when attacking the lower limbs as osteoarthritis. Damage to joints tends to be confined to a few joints and is slow and less destructive than that caused by rheumatoid arthritis. There is less upset to the system, such as anaemia, weight loss and fever also.

In addition flare ups from psoriatic arthritis usually settle down and may be followed by many years of remission during which time no drugs or treatment are required and the sufferer can lead a normal life. The dilemma for the rheumatologist in treating patients with PA is to try and identify those patients who belong to the group who will become severely

disabled. Except in a few cases this is not usually obvious in the first year of disease. Since the majority of patients will only be mildly affected, simple advice and local treatment together with minimal drug therapy is what is generally recommended. Early arthritis clinics are being set up now to try and address this problem. Although started for rheumatoid arthritis sufferers many patients with polyarthritis from other causes will be included in these clinics before a firm diagnosis is made.

Drugs used to treat any disease necessarily cause side-effects, many of them dangerous, others uncomfortable for patients. The treatments used in rheumatic diseases are no exception. Even the mildest of drugs available across the counter, such as paracetamol, aspirin or ibuprofen can cause indigestion or damage to the liver and kidneys if used long term. The more powerful anti-inflammatory drugs, which are only available on prescription, also have a larger incidence of side effects, particularly on the stomach. These newer drugs have certainly revolutionised the treatment of pain and inflammation and enable many patients to lead a normal and relatively pain free life. But they need to be prescribed with care and only after discussion between patient and doctor so that all the risks and benefits are understood.

The second group of drugs used suppress rather than cure the disease but they can cut short an attack and delay joint damage. They are more powerful and more specific but their side effects are worse and include

damage to the skin, kidneys, lungs, liver and bone marrow. Some of these side effects are life threatening. Although these side-effects can be minimised and most are reversible on stopping the drug, they do occur in quite a high percentage of patients and many people feel that the risks of taking the drugs are unacceptable.

A balance therefore has to be struck in deciding the treatment required for an individual patient, by putting on the scales on one side the risks of the disease to the patient and the likely benefits from the drug, and on the other the risks of side-effects. In many patients, the risks will outweigh the benefits. Nevertheless any patient should have a chance of discussion with their doctor, where the treatment available, the risks and benefits of drugs and the reasons for withholding drug treatment can all be explained. The right for these discussions and the chance to give informed consent for the use of drugs is fundamental to modern medicine. Sufferers from PA should be prepared to ask questions of their doctors during consultations and should equally be prepared to take decisions for themselves as to whether they will or will not accept modern drug treatment for their condition. Doctors should ensure they allow time for this discussion, understand the treatments available and the needs of each individual patient. Only with this partnership will everyone with psoriatic arthritis receive the best treatment and advice.

Dr. A. Virginia Camp

You and Your Diet

One of the main areas of interest in altering diet to help people with psoriatic arthritis, has been in the use of fish oils. More precisely it is the type of fatty acids present in large quantities in the fish oils which are of importance. These are known as the n-3 or omega-3 long-chain polyunsaturated fatty acids, eg DHA and EPA.

Evidence suggests that these n3 fatty acids may help with some inflammatory conditions such as rheumatoid arthritis but the beneficial effect in psoriasis is less certain. Large, double blind, placebo-controlled studies have shown that fish oil or fish oil combined with evening primrose oil, did not produce any clinical benefit in the treatment of psoriasis (Soyland et al 1993, Oliwiecki et al 1994). However another study concluded that dietary advice to include 170g of oily fish daily led to a modest clinical improvement in chronic-plaque psoriasis (Collier et al 1993).

There is good evidence that n3 fatty acids have an important role in maintaining heart health and can reduce the risk of having a fatal heart attack. The British Nutrition Foundation (1992) suggested an intake of 2-3 medium servings of oil-rich fish per week and the Dept of Health (1994) recommended an intake of one portion of oily fish per week. Examples of oil-rich fish are mackerel, salmon, kippers, herrings, sprats, trout, sardines and pilchards. Tinned tuna is not a good source because of losses incurred during processing.

Another fatty acid, alpha-linolenic acid, can be converted into n3 fatty acids in the body. Good sources of this are linseed (flax) oil, rapeseed (canola) oil, soyabean oil and some nuts, particularly walnuts. Meat and meat products and green leafy vegetables are also useful sources.

Fish liver oils, such as cod liver oil are rich in Vitamin A and D. These vitamins are very useful for the elderly and housebound but can be toxic if the recommended intake is exceeded. Fish body oils do not have these high levels of vitamins.

There is concern about various toxic compounds such as mercury, dioxins and polychlorinated biphenyls in oily fish and fish oils. The Food Standards Agency (FSA) published results of a survey of fish oil supplements bought from UK retailers and 2 brands were withdrawn from sale. However exposure to dioxins has decreased considerably over the past 20 years and the FSA has recommended that people should continue to eat oily fish regularly as part of a balanced diet to reduce the risk of heart disease.



In 1996 (Naldi et al) a study found that people with the highest intakes of fresh fruit, carrots, tomatoes and beta-carotene were less likely to have psoriasis. Beta-carotene is found in many fruits and vegetables, particularly yellow or red varieties. There is a clear link between eating a diet sufficient in fruit and vegetables and reduced risk for some



diseases, but the usefulness of taking betacarotene as a supplement is not established and may even be harmful. It seems to be the complex mixture of constituents in foods which is beneficial for health, rather than a high intake of one particular nutrient.

Both under-nutrition and obesity can be a risk with arthritic conditions. Poor nutrition, because of difficulties shopping and preparing meals will take it's toll on health such as in reducing immune function, muscle weakness, delayed wound healing and poor morale.

Obesity can easily develop when mobility is reduced or with an inappropriate dietary intake. Excess weight will increase the burden on joints and add to mobility problems. Losing weight means changing eating habits for ever, not just for a few months. Exercise is also important for weight control as well being essential to preserve strength and range of movement.

Health experts agree on the following advice to ensure a balanced diet and to help with weight control and prevention of common diseases:

- enjoy a variety of different foods
- eat plenty of foods rich in

starch and fibre

- eat at least five fruit and vegetable portions a day
- eat moderate amounts of lean meat or alternatives
- eat or drink moderate amounts of lower-fat milk and dairy foods
- eat fatty foods sparingly and choose lower-fat alternatives
- use less salt at the table and when cooking

Many people find it difficult to prepare foods and so their diet can be limited for that reason. Aids such as electric can openers are available in general and specialist shops. Different cooking methods such as stir-frying, microwave ovens and electric steamers can avoid the need to handle pans of hot water

New products available in supermarkets also take some of the work out of cooking. Hot food counters can offer ready roasted meats, and chilled counters have ready to eat smoked fish, low fat cheeses, salads and lean meats.

Increasingly people are using complete ready prepared meals. Choose meals with care, avoiding pastry and rich, creamy sauces which are high in fat. To help stay within healthy eating guidelines look for meals which are less than 20g fat and less than 2g salt (0.7g sodium) per

serving. Try to base the other meals in the day on simple, unprocessed foods, such as cereals, breads, fruit and vegetables.

So diet does not by itself hold the key to treatment of psoriasis, but it's influence on health as a whole is indisputable. Whatever our lifestyle we can aim for a balanced, enjoyable diet.

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Psoriatic Arthritis & Psoriasis

Conference 2003

Saturday 13th September 2003
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10th Anniversary
Reflections on Disease – Now and the Future

PROGRAMME

9.00-10.30 Registration		
10.30	Welcome	David Chandler
	Opening Remarks	TBA*
Session One		
	Health Provision and You	TBA
	Rheumatology for the 21st Century	Dr Virginia Camp
	Physiotherapy Now	Catherine Buckley
	Psoriasis Today	Dr Tony Chu
12.30	Lunch	
Session Two		
1.30	What do the tests mean? (+ handout of glossary of terms)	Dr Anthony White
	The Patient power and persuasion	Chris Friend Patrick Parker
3.00	Tea break	
Session Three		
3.15	The future-Questions & Answers	Expert panel
4.00	Close of conference	

*Subject to change

This conference is organised by the the Psoriatic Arthropathy Alliance. A national charity dedicated to raising awareness and helping people with psoriatic arthritis and its associated skin disorder, psoriasis.

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PSORIATIC ARTHRITIS *THE FEET*

When psoriatic arthritis (PA) presents as a polyarthritis it is probably just as common for it to involve the small joints of the feet, as the hands, although no reliable statistics exist to demonstrate this. The feet are also one of the sites for the occurrence of inflammation of tendon ends (enthesopathy) found at the tip of the calcaneum and Achilles tendon insertion in particular.

The presence of "sausage" toes is one of the "supportive" features in the criteria for diagnosis of PA. The pain of PA of the feet is often the dominant feature to sufferers and a potent cause of disability. It is surprising that descriptions of foot involvement in psoriasis (including the skin problems of onycholysis and plantar pustular psoriasis) are given so little prominence in textbooks.

In about 4% of patients enthesopathy may precede the onset of arthritis. Plantar fasciitis with calcaneal spur formation is the commonest type seen. Early morning heel pain and foot stiffness which resists all forms of treatment (eg injection, physiotherapy, heel pads) for 6 months, most particularly if bilateral should alert a clinician to the possibility of an inflammatory systemic condition. PA and seronegative spondylarthritis are the two commonest conditions that present like this and patients should be watched carefully. Enthesopathy may accompany all forms of PA in 40% of sufferers and may need specific treatment locally for symptom control.

Although PA can be confused with rheumatoid arthritis (RA), when it presents as a symmet-

rical polyarthritis of the metacarpal and metatarsophalangeal joints, it can usually be distinguished by involvement of other more specific joints and the absence of rheumatoid factor in the blood. It is more common for this type of arthritis to be assymmetrical and to involve only the first metatarsophalangeal joint, together with one or two interphalangeal joints. Erosions of many small joints may be seen on X-rays. The combination of erosion, absence of rheumatoid factor, sausage digits and involvement of the first interphalangeal joint is typical of PA. Other joints in the feet, especially the fifth metatarsophalangeal and ankle joints may also become painful and swollen but less commonly so.

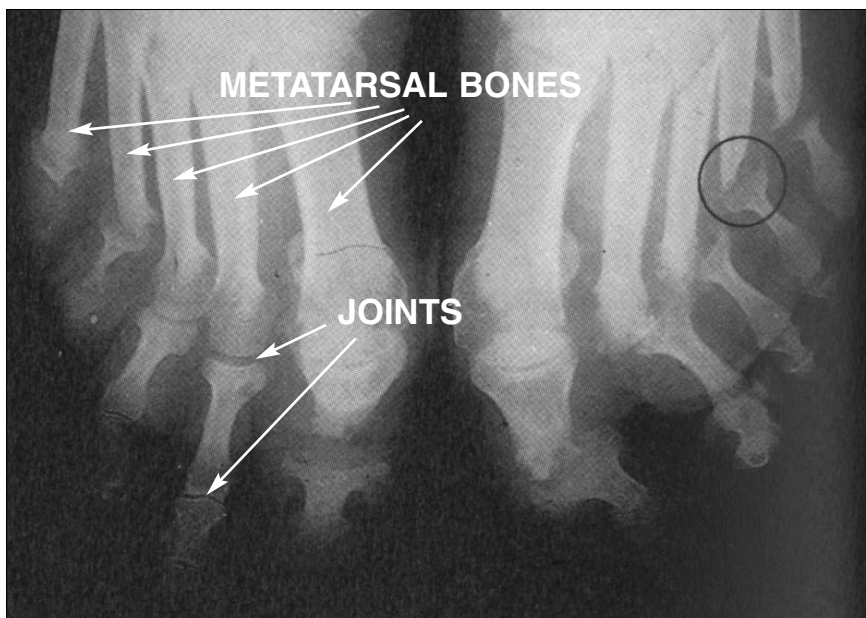
The initial symptoms of foot arthritis are of pain and swelling, warmth, and stiffness. Morning stiffness does occur in PA, but is far less dominant than RA. Evening stiffness and swelling with limited walking distance are the commonest problems to patients. The wearing of shoes for more than a few hours at a time and the need to change shoe height, weight and width two or three times a day are familiar features to patients and clinicians alike.

More long-term the feet can become deformed. This can occur remarkably quickly - within 6 months if the arthritis is not adequately treated. The usual deformities are clawed toes, hyperextension of the big toe and some inrolling of the ankle with flattening of the metatarsal arch. Stiffness of the joints rather than instability also happens quickly and can again become irreversible within a few months. The occurrence of calluses and ulcers on the soles of the feet is less common than in RA but



"corns" over the interphalangeal joints can be very painful.

Despite this seemingly depressing description, the nature of PA in the majority of cases, is to be milder than RA. The arthritis is more circumscribed, milder in onset and subject to long periods of remission. This means that disability is less but as far as the feet are concerned, can work against adequate treatment. Both patients and clinicians tend to ignore the symptoms and deformity and stiffness can develop insidiously. This leads to future problems including osteoarthritis, tendon contractures, calluses and disability. These features may be prevented if treatment is adequate.



The treatment of the feet in PA must initially include a full assessment of the involved joints and tendons. A walking assessment should be included together with the usual blood tests, full history and X-Rays. If suppressive medication is considered necessary this should be started promptly. The slow action (3 months) of such drugs means that any delay in initiating treatment can allow the development of erosions and deformity.

Local treatment to the feet is always necessary to some degree. This may include corticosteroid injections to the worst involved areas (painful but effective for up to 6 months), anti-inflammatory gels and physiotherapy. Anti-inflammatory and analgesic drugs will also be needed to control pain initially. The advice of a podiatrist(chiroprapist) should be sought also.

It is vitally important that the patient understands from the outset the importance of joint protection and exercise and the effects that weight-bearing and footwear can have both for good and bad on the feet. Advice early in the course of the arthritis from a physiotherapist and/or a podiatrist can do much to

prevent deformity. The patient should be told to remeasure length and width of his or her feet (not many adults bother to do this after the age of 21) and purchase shoes that are both wide, deep and long enough to encompass swollen feet, have deep soles and support of the arches and ankles. Invariably this excludes some female fashion shoes, although some modern boots are of excellent design. Clinicians can do no more about this potential battle-

ground than point out the dangers of unsuitable shoes. Unfortunately fashion and power dressing are the usual winners.

Patients also need to learn the type of mobilising and stretching exercises that will prevent stiffness and deformity. These should be carried out every day even when the arthritis is active and should always be done non-weight bearing. Massage baths, hand massage and gravity assistance can also be used for symptom control as part of the regime.

If deformity has already developed or if plantar fasciitis causes a painful limp, shoe inserts may be needed. Here a chiropodist or skilled orthotist can be invaluable. Silicone gel and various synthetic materials can help to redistribute weight. There is a new silicone gel and mineral substance incorporated into heel and toe caps which is proving very popular with patients which is now obtainable. Surgical shoes and more sophisticated splints are seldom necessary except for the severest cases. Similarly orthopaedic surgery for correction of deformed joints is only justified in the presence of long-standing deformity where pain is preventing adequate mobility and all alternative medical treatments have failed.

PA of the feet can be a potent cause of pain and disability. Adequate recognition and treatment of the problem is seldom ideal. If addressed early this form of arthritis can be properly treated and much future pain prevented. Such treatment needs a multi-disciplinary approach in partnership with the patient.

Author:
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Consultant Rheumatologist
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Alternative TREATMENT

To Whom it may Concern,

We would like to take this opportunity of introducing ourselves to you. This is the health department of BWDK Travel Group - Turkey the joint venture of Blue World Travel and Deren Koray Tourism official members of Turkish Republic Ministry of Tourism Licensed #: A-3885 #: A-2856

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We proudly announce that we have newly established an informative web site about psoriasis and the natural treatment method of the doctor fish. Here are the relevant information that can be found on the web site:

www.psoriasisfishcure.com.

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The reason we are writing to you is to see whether we can be of any service to either your organisation, to your patients or to the people around having psoriasis disease. BWDK will be pleased to assist the patients by serving and arranging all necessary arrangements, to work with your association regarding the possible treatment packages for the patients, arranging hotel accommodations, the necessary transfers, treatment sessions and anything else you may require as well as providing detailed information for your kind attention.

If you need further assistance I'd be pleased to help you personally on behalf our company.

Best regards,

Koray Altan, M.Sc.,

BWDK Travel Group - Turkey
Manager

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Dear UK PA people...

I hope this may be of help to some of your members. Living in Australia and not being a member of your Society I'm not sure if this advice has often been given to your members before...

My husband Brian has suffered from PA for some years. The last couple he has been feeling very tired, its really affected his life-style. He blamed his Methotrexate. I told him tiredness was also a symptom of the disease itself. Then a blood test showed he had very low iron levels (but not yet anaemia). Luckily his rheumatologist

galvanised into action to find the cause. Following further tests its been established he has coeliac disease (the Americans spell it celiac), which of course is a food intolerance which badly upsets the small intestine and is treated by following a gluten-free diet. I've been researching low iron and heard that this can have several other causes, one of course being colon cancer. Another I heard of was a stomach virus called helicobacter, and in developing countries its likely to be hookworm.

My point is that PA sufferers feeling extreme fatigue should get their iron levels tested. They

should go off their iron supplements for a couple of weeks first if they take them. If low iron is found they need to find out the cause as soon as possible. (High iron levels are dangerous too).

I'm hoping a change of diet will improve Brian's skin and arthritis -- I'm not saying his coeliac disease caused his PA, but anything which stresses the body (and in this case, may let toxins into the blood stream) certainly wouldn't help.

**Maggie Eibisch
Canberra**

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B	U	I	O	P	P	S	O	R	I	A	T	I	C	V	U	T	I	C	E

FIND THE WORDS!!

ARTHRITIS
 ARTHROPATHY
 BONES
 CREAMS
 COMPLIANCE
 CONFERENCE
 CURE
 DEAD SEA
 DISCRIMINATION
 DRUGS
 ESR
 FEET
 FINGER
 FLARE
 GENES
 CLINICAL TRIALS
 xRAYS
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 JOINT
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 TREATMENTS
 NICE
 NHS
 PAIN
 PATCHES
 PSORIATIC
 PSORIASIS
 PUSTULAR
 PUVA
 RESEARCH
 SKIN
 STRESS
 TABLETS
 TOE
 TRIGGERS
 REDDISH
 RHEUMATOLOGIST

MEMBERS OF PARLIAMENT MOVE TO PROMOTE THE CAUSE OF ARTHRITIS

More than 100 Members of Parliament have signed an Early Day Motion (EDM) calling on the Government to make arthritis a health priority – proving that MPs do listen, said Neil Betteridge, head of public policy and campaigning at Arthritis Care.

The motion – a petition that politicians sign to record their support for an issue – was tabled by Labour MP Roger Berry, and simultaneously supported by Conservative MP Tim Loughton and Lib-Dem Brian Cotter.

It follows a successful reception at the House of Commons, held by Arthritis Care and ARMA (The Arthritis and Musculoskeletal Alliance) which encouraged people with arthritis to lobby their MP's for help in accessing treatments.

'Although arthritis affects one in five of the population and is the single biggest cause of physical disability, it has never been a health priority; and post code prescribing still exists,' said Betteridge.

'But despite the fact that there are many other concerns for politicians right now, they have taken the time to listen to us and support our cause,' he added.

'We have proof that political pressure and commitment can change things for the better for people with arthritis. In Wales, for example, the Welsh Assembly has committed itself to setting up a national strategy for arthritis. And it looks as though Scotland and Northern Ireland may follow.'

'It's a long overdue development, but the fact that so many MP'S have signed the Early Day Motion proves that they are taking the condition more seriously.'

'We know there are still significant barriers to best practice and access to treatments in this country. For example, many rheumatology services are inadequately funded, and there is a lack of multi disciplinary teams. Hydrotherapy services are closing down or are inaccessible, and there is not enough funding for new medical treatments – despite them having been approved and recommended for use.'

'However, the long waiting times for orthopaedic surgery are being addressed – not quickly enough for many people – but there is hope on the horizon.'

'Receiving cross party support from more than 100 MP's sends a clear message that arthritis is now firmly on the political agenda across the UK,' he added.



Unmistakable



Unpronounceable

Unguentum M for eczema and dermatitis is a little bit unusual, because although it works like an ointment, it vanishes like a cream. If that sounds good, talk to your pharmacist and remember to ask for it by name. If you dare!

TM

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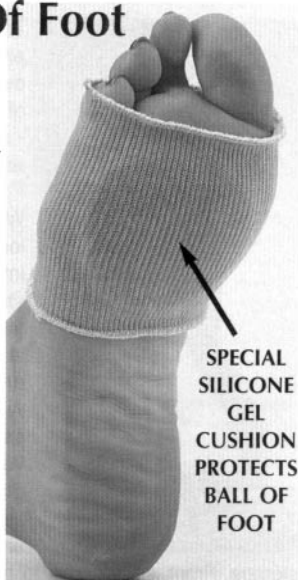
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Gel Cushion Protects Ball Of Foot

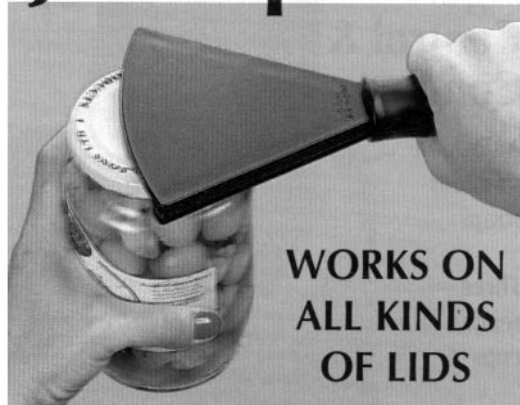
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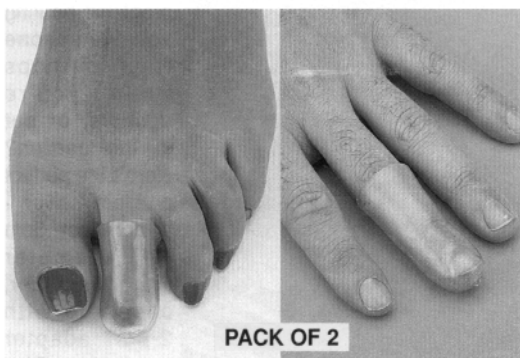
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PUSTULAR PSORIASIS

Pustular psoriasis tends not to look like ordinary psoriasis although ordinary and pustular psoriasis can coexist or one may follow the other.

The main distinguishing feature of pustular psoriasis is the appearance of pus spots surrounded by red skin. However this does not mean that there is any infection present. They simply show that the skin has been invaded by the same white blood cells that would be seen if there were to be an infection present.

TRIGGERS:

It can be provoked by some internal medications, irritating topical agents, ultraviolet light overdoses, pregnancy, systemic steroids, especially sudden withdrawal of systemic or topical steroids, infections, perspiration or emotional stress.

PALMAR - PLANTAR PUSTULOSIS (PPP)

A form of pustular psoriasis which can occur in people between 20 and 60, which causes pustules on the palms and soles of the feet. Infection and stress are suspected triggering factors. PPP is normally recognisable by large pustules approx up to 5cms, in fleshy areas of hands and feet, such as the base of the thumb and the sides of the heels. They then turn brown and desquamate or peel. PPP is usually cyclical with new crops of pustules followed by periods of low activity.

This type of psoriasis is recognisable by white or yellow pus spots, which turn a darker yellow after a few days and

eventually, drop off. This form of psoriasis affects approximately 5% of people with Psoriasis.

It tends to go in cycles of :-

1. Erythema (reddening of the skin) followed by
2. formation of pustules and
3. Scaling of the skin.

Topical treatments are usually a first line treatment. PUVA, methotrexate are also sometimes used to clear the attack.

In most episodes of pustular psoriasis these will last for a few weeks then disappear or remit to erythrodermic psoriasis

Another rarer type of psoriasis is generalised pustular psoriasis also known as Von Zumbusch's disease, which can be abrupt, and can be triggered by an infection, pregnancy, low thyroid activity and drug involvement. It can cause fever, chills, severe itching, rapid pulse rate, exhaustion, anaemia, weight loss, and muscle weakness and joint pains. Sometimes these attacks are followed by milder outbreaks of psoriasis.

With this type, which can also rarely appear in children, the pustulars occur all over the body, this type often requires hospital in stay treatment. It must be stressed that Generalised Pustular Psoriasis is a rare form of psoriasis.

TREATMENT: GENERALISED PUSTULAR PSORIASIS

The main aims of the treatment is to restore the skin's barrier function, prevent further loss of fluid, stabilise the body's temperature and restore the skin's chemical balance. Imbalances, which can occur,

can put added strain on the heart and kidneys, especially in older people. Because of possible complications with this form of psoriasis medical care must be sought immediately, with the likelihood of hospitalisation for a short period of time depending on the severity of the outbreak.

When hospitalised, bed rest, mild sedation, bland topical therapy, rehydration and avoidance of excessive heat loss can improve the situation. In some cases antibiotics are prescribed just in case of infection is also present. In severe cases where the patient has become exhausted other medications may be needed.

Methotrexate is a common used treatment for generalised pustular psoriasis. Oral steroids are often prescribed for those who do not respond to other forms of treatment, or have become very ill, but their use is very controversial. PUVA (the photosensitizing drug psoralen plus UVA light) may also be used in the treatment of this condition after it has subsided. cyclosporine is also a medication that is used.

In most episodes of pustular psoriasis these will last for a few weeks then disappear or remit to erythrodermic psoriasis.

ACRODERMATITIS CONTINUA OF HALLOPEAU

Another rare form of palmar-plantar pustular psoriasis characterised by skin lesions on the ends of the fingers and sometimes on the toes. The eruption occasionally starts after local trauma. Often the lesions are painful and disabling, with the nails often deformed, and bone changes may occur. Treatment for this condition is quite hard to treat satisfactorily.

PSORIASIS - What's not often talked about...

PSORIASIS AND THE GENITAL AREAS

Yes, psoriasis in the genital region is distressing, but if it makes you feel a little better, which I doubt, its common in many patients. The mere mention of genital psoriasis I'm sure makes most of us cringe and cross our legs, and our eyes water at the thought of it all, and pray it doesn't happen to us.

For some, psoriasis is just confined to the genital region. In men, parts affected are the penis, circumcised or not, the condition manifests itself as either small multiple red patches on the skin, scrotum, (occasionally scaly patches can occur, pubic area, (this often resembles scalp psoriasis), the anus, especially the crease between the buttocks, upper thighs adjacent to the groin, the psoriasis displaying itself usually as red sore looking patches, which are often non scaly in appearance, although possibly itchy sometimes, being most uncomfortable in hot weather due to heat and sweat. The skin affected between the buttocks can at times also appear cracked. In women, the parts affected can be the perineum, (skin between the anal outlet) and vulva, as well as the skin around the anal outlet. The affected vulva can appear as smooth non-scaly redness, and may weep if it scratched too much, which is not advisable in case of infection, due to irritation

Some of us may never have patches anywhere else on our bodies only in than in this region, whilst for others, psoriasis appears on other parts of the body as well.

You are not going to like the next bit much either. But a word of caution needs to be said. If you think you suffer from this form of embarrassing psoriasis affliction in your nether regions, please get it looked at by your doctor or dermatologist, as it might not be genital psoriasis but something else which can be easily treated that has been caused by clothing or a yeast infection. For a few minutes mental discomfort at the mercy of

your doctor, may put you out of your misery and gain you some relief.

If you get a correct diagnosis you can get appropriate treatment, and there are things that can be done to help you. Have courage to bare all.

Psoriasis itself can cause many emotional problems for those of us who have the condition to conqueror at sometime in our lives, be it when we are young or older, but for those with genital psoriasis, the problem can be a nightmare, especially where new relationships are concerned. How do you explain what the sore, angry looking red patches are around your groin area, or to explain that your penis is not a harmful, contagious instrument to your partners vagina, but that you suffer from a common skin disorder that is frustrating, distressing and irritating but not harmful.

This subject is not the sort of thing you talk about over a first date romantic dinner for two, but sooner or later you know you have to prepare yourself for those awful questions, and dread that first session of passion, where of course undressing is the name of the game. If the lights are out you can relax, and work on your plan of action on how to break the news to your new partner for the next time round.

Emotional turmoil and anxiety are foremost, but don't be put off by embarking on relationships they are difficult to build on at the best of times. You are no lesser person for having a skin disorder than those who don't.

HANG UPS do not get any of us anywhere. An understanding partner makes the world of difference, so if you are starting out on new relationships, have confidence in yourself, take things slowly and gently, more importantly RELAX and enjoy your time together, building a firm relationship for the future.

I'M FINE, THANK YOU.

There is nothing the matter with me,
I'm as healthy as I can be,
I have arthritis in both my knees,
And when I talk, I talk with a wheeze.
My pulse is weak and my blood is thin
But I'm awfully well for the shape I'm in.

Arch supports I have for my feet
Or I wouldn't be able to be on the street.
Sleep is denied me night after night,
But every morning I find I'm all right.
My memory is failing, my head's in a spin
But I'm awfully well for the shape I am in.

The moral is this as my tale I'll unfold,
That for you and me who are growing old,
It's better to say: 'I am fine' with a grin,
Than to let folks know the shape we are in.

How do I know that my youth is all spent?
Well, my get up and go has got up and went.
But I really don't mind when I think with a grin
Of all the grand places my get up has been.

Old age is golden I have oft heard it said,
But sometimes I wonder as I get into bed,
With my ears in the drawer, my teeth in a cup,
My eyes on the table until I wake up,
Ere sleep overtakes me I say to myself,
'Is there anything else I could lay on the shelf?'

When I was young my slippers were red,
I could kick my heels right over my head.
When I was older my slippers were blue,
But still I could dance the whole night through.
Now I am old, my slippers are black,
I walk to the store and puff my way back.

I get up each morning and dust off my wits,
I pick up the paper and read the obits,
If my name is still missing, I know I'm not dead
So I have a good breakfast and go back to bed.

Anon:

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Copies of current and back issues of PAA publications are available at the costs set out below.

PLEASE indicate which publication(s) you require, and return this form with your remittance.

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Newsletter	7	September 1996	£3.00		
Skin 'n' Bones Connection	7	December 1996	£3.00		
Newsletter	8	March 1997	£3.00		
Skin 'n' Bones Connection	8	Summer '97	£3.00		
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(Completion optional and confidential)

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

How long have you had PA?

How long have you had Psoriasis?

Areas/joints affected?

Medication tried (please list)

Current Medication taken? (please list)

Any family history of PA 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
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The funds - distributed by the Calvert Trust - were raised by donations from Zurich Financial Services staff with matched funding from the company.

The grants allow up to 150 physically disabled people across the UK to develop their confidence and potential through attending Calvert Trust activity centres in Devon, Northumberland and Cumbria this year. Now in their second year, the grants are part of a three year partnership with the charity worth a total of £150,000.

John Fryer Spedding of the Calvert Trust Council said:

"This is the second tranche of money Zurich has made available to the Trust as part of a three year deal. Last year, nearly 170 disabled people and carers were supported by Zurich grants. We are delighted that more disabled people, who otherwise would never have the chance to attend, will benefit from our activity centres this year"

The bursaries are available to people dependent on Disability Living Allowance or who can provide evidence of need.

Each of the three Calvert Trust centres provide specially equipped accommodation with both self catering and fully serviced facilities. Activities are managed by highly skilled teams of specially trained instructors and are available to people of all abilities.

Applications for grants should be made direct to the Calvert Trust centres.

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