Contributors: GE Gray was responsible for the conception, development, and overall writing of the article; she is also the guarantor. JAMcI provided the case report, gave obstetrical input, and helped to edit the manuscript.

Competing interests: None declared.

Provenance and peer review: Commissioned; externally peer reviewed.

- 1 Mofenson LM. Mother-child HIV-1 transmission: timing and determinants. *Obstet Gynecol Clin North Am* 1997;24:759-84.
- 2 Gray GE, McIntyre JA. Effect of HIV on women. *AIDS Reader* 2006;16:365-8, 373-7.
- 3 Saada M, Le Chenadec J, Berrebi A, Bongain A, Delfraissy JF, Mayaux MJ, et al. Pregnancy and progression to AIDS: results of the French prospective cohorts. SEROGEST and SEROCO Study Groups. *AIDS* 2000;14:2355-60.
- 4 Burns DN, Nourjah P, Minkoff H, Korelitz J, Biggar RJ, Landesman S, et al. Changes in CD4+ and CD8+ cell levels during pregnancy and postpartum in women seropositive and seronegative for human immunodeficiency virus-1. *Am J Obstet Gynecol* 1996;174:1461-8.
- 5 Tuomala RE, Kalish LA, Zorilla C, Fox H, Shearer W, Landay A, et al. Changes in total, CD4+, and CD8+ lymphocytes during pregnancy

and 1 year postpartum in human immunodeficiency virus-infected women. The Women and Infants Transmission Study. *Obstet Gynecol* 1997;89:967-74.

- 6 Lewis G. *Confidential enquiries into maternal deaths: beyond the numbers: reviewing maternal deaths and complications to make pregnancy safer*. Geneva: World Health Organization, 2004:77-102.
- 7 Mofenson LM. Efavirenz reclassified as FDA pregnancy category D. *AIDS Clin Care* 2005;17(2):17.
- 8 US Food and Drug Administration. FDA Public Health Advisory for Nevirapine (Viramune). 19 January 2005. www.fda.gov/cder/drug/advisory/nevirapine.htm.
- 9 British HIV Association. Guidelines for the management of HIV infection in pregnant women and the prevention of mother-to-child transmission. *HIV Medicine* 2001;2:314-34.
- 10 World Health Organization. *New data on the prevention of mother-to-child transmission of HIV and their policy implications, conclusions, and recommendations*. WHO technical consultation on behalf of the UNFPA/UNICEF/WHO/UNAIDS Inter-Agency Task Team on Mother-to-Child Transmission of HIV, Geneva, 11-13 October 2000. Geneva: WHO, 2001.

A PATIENT'S JOURNEY

Psoriasis

Ray Jobling

Psoriasis Association, 7 Milton Street, Northampton NN2 7JG
rgj1000@cam.ac.uk

BMJ 2007;334:953-4

doi: 10.1136/bmj.39184.615150.802

In 1955, I was 14 years old and just diagnosed with psoriasis. I didn't know it then of course, but it would never go away. Psoriasis and its treatment were to be part of my life for the next 50 years and more.

My general practitioner gave it no name, but said it was common and could just go away. He said I might "grow out of it" and that I should get used to it, "learn to live with it." This attitude scarcely prompted confidence in his prescribed tar ointments and baths—as noxious and loathsome in use as they were ineffective in action. He seemed unsurprised that I returned worse rather than better. By now the pink patches were large, numerous, and widespread. My body looked like an old map of the British Empire. The lesions grew fiery, scaled profusely, and crumbled messily. They bled; I looked and felt a mess.

I was dispatched to a dermatologist. I had psoriasis—no more information let alone an explanation was forthcoming. I was to redouble my ointmenting efforts. Perhaps, it was alleged, my (the family's) compliance had not been strict enough, a ludicrous accusation for we were dutifully dedicated to the demanding daily rituals of topical treatment. We pressed on for months. Tar gave way to anthralin (dithranol), which stained me as much as my clothing and bed linen. Life was punctuated by endless clinic encounters with a bewildering succession of skin doctors. I was repeatedly, rather routinely, told that I was not ill and must not think of myself as such. I had to live a normal life. It was after all no more than a "benign" condition. Later, I heard a dermatologist tell his students as I departed the consultation, "Not very interesting that one, just another very ordinary psoriasis." If there was any awareness of the practical, psychological, and social complexities involved, no explicit interest was shown, and neither assistance nor advice was offered.

Not ill then, but obviously a permanent patient, I found myself in a strange and perplexingly ambiguous position. For someone who was not ill—I was otherwise in robust rugby playing good health in fact—I spent a puzzling amount of time in consulting rooms or clinics and labouring away at treatment. The demanding treatment regimens, which at times took more than 20 hours a week, brought scant reward. "Clearance" seemed to be the goal, but even improvement was only ever partial and dispiritingly temporary—remission was impossible. I was engaged in a relentless physical assault on my symptoms, at war with my skin . . . and inevitably losing. The disease and its treatment merged, combining inextricably to impact upon my personal experience and social identity; a sad fact that both were in effect demeaning. Skin disease can stigmatise. Stripped of my clothes I looked strangely, perhaps threateningly, different. I understandably attracted unwanted attention. Although rare, revulsion and rejection were an ever present threat. What appeared to be breadcrumbs were scattered through my hair. I shed a constant shower of scaly detritus, leaving my mark wherever I went. Daily applied tar meant that I smelled like a newly paved road. If it rained my hair gave off a sickly odour. Even my winter tan (derived from treatment) set me apart. No one from my world jetted to beaches or ski slopes in the 1950s.

Thus, I grew up with it. Years and life unfolded, offering new opportunities and experiences, but also demanding adjustments. I had long wanted to join the Navy. No one doubted my physical fitness. I spent months competing for officer selection, but I was inevitably rejected on medical grounds—I was hugely disappointed. Those who had insisted that psoriasis was not an illness had neglected to tell me that it could still be a handicap. I took my psoriasis and its treatment

A DOCTOR'S PERSPECTIVE

I first met Ray when I was a newly appointed consultant with six years of training in dermatology and no personal experience of dealing with severe psoriasis. He was already 36 years into his journey, in many ways far more an expert than myself. From Ray, I have learnt something of what is really wanted from dermatologists, including recognition of the burdens of continuous treatment—the time, the labour, and the impact on partners and families. Realism and understanding about compliance is needed—appreciation of the patient's experience of the repetitive relentlessness of it all. Even clearance is accompanied by threat—rollercoaster improvement and relapse do damage. As Ray has said, compromise and balance are the order of the day. New treatments call for wariness. Optimism about a “breakthrough” can be followed by failure that is devastating for the morale, which is bad for doctors but worse for patients.

Effectiveness in long term management involves more than short term drug efficacy. Partnership, mutually respected expertise, shared perspectives, and agreed goals all matter. The selection of treatment and evaluation of benefit should be joint endeavours. The patient needs to feel that as much as possible he or she retains responsibility and control of the condition, the treatment, and their impact on life.

Crucial too, is ready accessibility in time of crisis. We share concern that no well intended healthcare reorganisation, by introducing extra steps and barriers in the patient journey, should threaten confinement to a place in the care system that cannot, with the best will, offer the qualities necessary for good long term management. The outcome would be immense frustration and damage to wellbeing, but also potentially disastrous delays in treatment of a severe exacerbation.

Paul Norris consultant dermatologist, Addenbrooke's Hospital, Cambridge CB2 2QQ

away to university, for better or worse to be a sociologist. My skin got no better. The treatment changed a bit, but did not noticeably improve. Topical steroids came in during the early 1960s, when I was in my 20s. I crackled and snapped, sweated and stank through many student days in an occlusive polythene body suit. It felt as though I was being boiled alive. An acute flare-up put me in hospital for weeks. If my self esteem was affected by the disease, the treatment made the damage worse.

After graduating and getting married I took an academic post and moved—new place, same treatments, same disappointing outcomes. My wife shared the caring load. I was and remain immensely grateful for her positive acceptance and total support. We went to Canada for a year before settling in Cambridge. It was then that I became involved with the Psoriasis Association. It transformed my life—informing and shaping my perspectives, raising my sights, and improving my “vision.” I was encouraged to find my own voice. I began to speak and write about the experience of psoriasis. The association has been better for my morale than any medicine.

As I grew into my mid-years there were therapeutic innovations—PUVA (phototherapy with psoralens and ultraviolet A), retinoids, etc. These were useful but not the final solution some promised. Psoriasis remains a chronic disease—impossible to eliminate, difficult to manage, potentially prejudicial to wellbeing. The treatment on offer fails to live up to the unrealistically optimistic, sometimes misleading, promises of the drug companies. And I have developed a healthy scepticism on that front. The clinical trials leave much to be desired; in reality, treatment decisions rest more on culture and tradition, individual practitioners' preferences, and corporate promotional pressure than on evidence from research.

Yet matters have improved. I have become clearer about objectives in treatment. I want as little treatment as possible—simple containment, acceptable equilibrium, manageability within the framework of everyday life—not constant battling to beat the disease into submission, which is doomed to failure and results in disappointment and distress. Treatment must be enduringly effective in this limited sense, practical, with few side effects, and safe in the short term and the long term. Compromise is a must. Given that topical treatment predominates, in reality complete adherence to the prescribed regimen is unrealistic, and probably not even desirable.

For me, real progress has come from developing excellent working partnerships with the medical professionals I consult, who offer support well beyond the prescription pad. Fortunately, I benefit from long term continuity of care from an experienced general practitioner, a skilful dermatologist, and specialist nurses. They know me, my skin, and my life, and they appreciate that there is far more to skin disease than mere disease of the skin. Naturally I am grateful for their technical expertise, but I also appreciate their understanding, concern, support, and beyond all else quiet encouragement—qualities and professional skills essential to good long term care.

Psoriasis is a chronic disease, a lifelong commitment. Disease and treatment shape a person's identity. The practical and psychosocial impact of the disease, like its physical expression, waxes and wanes. For most patients it need not overwhelm them—they can thrive in spite of it. Professional partners help by understanding the complexities, respecting the legitimacy of patients' perspectives and preferences, informing joint decisions, and never imposing their views or preferences on the patient. When clinical judgment so demands, urgent intervention can be vital too. For my part, I cooperate thankfully with medical efforts to restore equilibrium when temporarily lost, shifting gear into acute care, but trusting none the less that I can return to the long accustomed normality of an ongoing journey.

Contributors: RJ wrote the main article and PN supplied the box.

Competing interests: None declared.

Provenance and peer review: Commissioned; not peer reviewed.

RESOURCES

Psoriasis Association (www.psoriasis-association.org.uk)—Supports people who have psoriasis, raises awareness of psoriasis, and funds research into the causes of and treatments for psoriasis

National Psoriasis Foundation (www.psoriasis.org)—A US non-profit organisation dedicated to educating, serving, and empowering people with psoriasis and psoriatic arthritis

Psoriasis Association of New Zealand (www.everybody.co.nz)—Educates people with psoriasis, their associates, and the public about psoriasis and its treatments. It supports patient and their associates, distributes information and research results, and encourages research into new treatments and potential cures. It has established regional support groups