



**All Party Parliamentary Group on Skin
Inquiry into the Psychological and Social Effects of Skin Diseases
Oral Evidence Session**

**Tuesday 20th November 2012
House of Commons, Committee Room 15 (2.00pm-4.00pm)**

The Questioners

- Sir Paul Beresford MP (Chair, APPGS)
- Dr Susannah Baron (Consultant Dermatologist)
- Dr Antony Bewley (Consultant Dermatologist)
- Carole Easton (Deputy CEO, Changing Faces)
- Nick Evans (Patient and long-standing NHS employee)
- Baroness Masham of Ilton (Vice-Chair, APPGS)
- Dr Sandy McBride (Consultant Dermatologist)
- Dr Reena Shah (Clinical Psychologist)
- Lynette Stone (Former Chair, Skin Care Campaign)
- Tania von Hospenthal (BAD, Clinical Services Manager)

The Witnesses

- Mandy Aldwin (Ichthyosis patient) - MA
- Margaret Cox (NES, Eczema patient) - MC
- Ray Jobling (Chair (Psoriasis Association; Psoriasis patient) - RJ
- Maxine Whitton (Vitiligo patient) – MW

Order of the Proceedings

The format of the hearing was very similar to that of a parliamentary select committee.

A panel of questioners (listed above) was tasked with asking the witnesses a series of pre-prepared questions on a range of different areas related to skin disease. The questions were pre-prepared in order to ensure that the evidence was as structured as possible. Questioners were permitted however one follow-up question of their choice; this supplementary question had to be related to the previous question.

As expected, the answers to the questions overlapped somewhat in terms of the topics covered. For this reason, the recorded answers to each question varied in length.

The witnesses were given a general idea as to the types of questions they were likely to be asked before the hearing. This helped the witnesses prepare their answers more fully, which again ensured the smooth running of the session.

Questioners asked their allocated questions in a predetermined order. Whilst the questions were prepared in advance, questioners were free to suggest alternative questions in the run up to the day of the hearing.

The session was recorded and stored in an electronic audio file.

Summary of the Proceedings

Baroness Masham of Ilton

Q1) Could you please describe the nature and symptoms of your condition?

MW - described the nature and symptoms of her condition – vitiligo. The condition resulted in the loss of pigment in the skin; it usually resembled milk white patches and was due to the malfunction or destruction of pigment cells. The condition was estimated to affect around 1-2% of the world's population.

There were two main types of vitiligo. There was the non-segmented form, which was the commonest form and then there was segmented vitiligo, which tended to affect the skin in a more unilateral, unsymmetrical manner.

The condition could make itself apparent at any age but half of all cases tended to appear before the age of 20. Furthermore, it could affect any part of the body; in some rare cases, it could result in universal pigment loss.

RJ - described the nature and symptoms of his condition – psoriasis. The condition was prevalent in around 2% of the population and could appear at any age and on any part of the body. Psoriasis typically involved plaques on the skin, which would build up and shed continuously. The skin could become dry and cracked and although it was treatable it was not curable. It was essentially a life-long condition.

MC – described the nature and symptoms of her condition – eczema, sometimes also known as dermatitis. The term eczema was an umbrella term in itself, encompassing a myriad of different variations. One of the most common was atopic eczema. Caused by genetics and a number of environmental factors, the condition typically resulted in intense itching and soreness.

Often perceived as a childhood condition (1 in 5 children) it also affects a large number of adults (1 in 12 estimated to retain eczema from childhood).

MA – described the nature and symptoms of her condition - ichthyosis. There were many different types of the condition and variants were still being discovered. The main issue for patients with the condition was severe dry skin. This occurred all over the body and the treatment involved lots of emollients applied regularly.

The condition could flare up causing severe soreness and mental distress. The condition also left patients prone to allergies and could cause hair abnormalities.

Supplementary Question) With skin being such a diverse problem do you think with the new NHS it should be health and public health coming together to try and solve some of the problems?

RJ - thought there was an argument for more integrated care and a greater more considered approach to countering the stigma associated with skin disorders.

'There's more to skin disease than disease of the skin'

There needed to be some form of communication at the community level between various health professionals. This was particularly important given the social effects of skin disease which if ignored could impose an avoidable burden - perhaps especially during the teenage years when individuals are subject to an array of social pressures and expectations.

Tania von Hospenthal

Q2) How does your condition affect your ability to work or study?

MW - said that when she was working as a teacher her hands were quite badly affected and this was often pointed out by students.

She said that she had heard of a case through the vitiligo society where a midwife had been told that she could not deliver a baby due to the vitiligo symptoms on her hands. She had also heard of people struggling with job interviews.

'Because you're lacking in confidence, you're less articulate, you present yourself worse and you're less likely to get a job as a result. This can be a real disadvantage.'

Bullying was also common in the workplace and this could lead to stress and ultimately resignation from the job.

RJ - said that it didn't affect him personally in a work sense but through his involvement with the Psoriasis Association he had heard of examples where it had affected people.

His school years had been affected, not least because of the demands of topical treatment, especially tar-based products which entailed an unpleasant smell. UV treatment brought with it an unusual dark tan, prompting unwanted questioning. He had also encountered racial abuse based on his skin colour.

The biggest impact in terms of a career however was when the condition resulted in an unanticipated failure of a medical examination. As a result he was not awarded a scholarship for Officer Entry to the Royal Navy. At the time it had been a serious disappointment.

'It changed my life at the time... I felt at the time it had destroyed my life.'

MC - said she could work and study but throughout her life she had always struggled to manage the condition and its symptoms alongside her professional life.

'I struggled hugely as a youngster... because of the unremitting itch, I slept very poorly and to this day, I have a completely strange sleep pattern.'

'I have throughout my life lost huge amounts of time due to my eczema... even now I lose something like two hours a day to putting creams on and waiting for them to go in'.

She said that her condition played a part in her decision to stop practicing as a commercial lawyer. Despite being a partner in a large firm, the working hours did not work around her treatment routine and the dress code often caused problems. Furthermore, absences from work due to hospital and GP appointments were not understood or appreciated by colleagues.

MA – said that she also lost around two hours a day due to the treatments, but this had always been a fact of life for her.

She had had to take time off from school growing up but the condition was largely managed. The condition did flare up again however later in life, at one point it prevented her from pursuing a career in the airline industry.

She said that she felt she would be unable to go back to doing an office-based job in future because of her condition (soreness and pain causing lack of concentration, management of treatments, time off from work for hospital appointments etc.).

Through the Ichthyosis support group she had also heard of a number of other people having to take time of school and work due to their condition.

RJ – said that for many years the total time spent each week applying treatments could equate to half a week's working hours or up to three hours a day. When added to one's actual working hours, this was a substantial figure.

Supplementary Question) You mentioned time off due to the treatments, but have you ever had to take time off due to stress, anxiety or lack of confidence in your ability to go out there and 'face the world'?

MA – said that the soreness of the skin often affected her psychologically and she often felt like she didn't want to go out to work, go shopping or go on public transport.

MC – said that her condition had affected her psychologically. She often hated having to have her photograph taken and she found it incredibly hard to do media work which required meeting a number of new people. It took 'real guts' to go out and meet people on a daily basis.

RJ – said that he had had to take time off of work because of his condition for hospital appointments etc. but not for reasons related to anxiety and/or lack of confidence.

MW – said that she had not felt the need to take time off of work as her condition was largely hidden the majority of the time e.g. through facial skin camouflage.

Nick Evans

Q3) Does your condition stop or limit you from taking part in social or sporting activities?

MW – said that it did but not to the same extent that it did when she was younger. Anything that involved taking one's clothes off was always hard such as swimming. In Summer she would often

struggle to find clothes that would cover her arms whilst keeping her cool. There wasn't a top in her wardrobe without sleeves for 15 years.

Holidays were generally a 'nightmare' and she used to doubt her chances of having an intimate relationship with someone. Her relations with the opposite sex were 'limited' for several years.

RJ – said that it didn't prevent him from doing anything. There was something of an issue when he was younger, but he had found it manageable.

MC – said that anything that required taking one's clothes off was strongly avoided. As a child she also avoided physical education lessons. Sporting activity increased one's body temperature and this often worsened the itchiness of the skin.

She said that she did not feel comfortable going into large rooms full of people she did not know and social interaction was still hard despite the many years since she was first diagnosed. She often felt that others were staring at her skin.

Supplementary Question) Do you think skin conditions should be considered as disabilities - socially not medically?

MA – said that she would she would be inclined to say yes some days, other days, no.

RJ – said that it depended on the definition of a disability. He believed that there was much to be learned from an approach founded on the application of the "social model of disability".

MC – said that eczema was often trivialised and the debilitating nature of it was often ignored or dismissed. She said diabetic people often evoked strong sympathy and understanding, but eczema did not. You were expected to just get on with it.

Lynette Stone

Q4) When did you first develop your symptoms of your skin disease and when was this actually diagnosed?

MW – said that she was diagnosed around the age of 11 or 12 when she scratched her skin and the scar tissue lost its pigment. It then spread gradually over the years.

RJ – said that he was diagnosed around the age of 14 through the usual GP/dermatologist referral process. He said that he felt that this process had 'possibly' improved since he was first diagnosed. That said, he was anxious about current developments such as internet-based diagnosis & prescription, without much pretence towards careful management.

MC – said that she first developed symptoms aged 3 months old. She never 'grew out' of this 'childhood eczema'.

MA – said that she was born with ichthyosis but only became aware of her particular type of ichthyosis aged 12.

Supplementary Question) Do you think prompt/correct diagnosis is still a problem?

MA – said that she felt doctors needed to be honest with patients in doubt as to a diagnosis. This was far better than being told one thing and then another at a later date.

RJ – repeated that it could get better & might be getting worse in some ways.

MW – said that Vitiligo could still be misdiagnosed by GPs, confused with other skin conditions such as pityriasis versicolor which is caused by a yeast. The treatment is Selsun shampoo or anti-fungal creams which have no effect whatsoever on vitiligo.

Dr Reena Shah

How does having your skin condition make you feel on a day-to-day basis, for example does it make you feel low, anxious, self-conscious?

MW – said that she could get very low and had often lacked self-esteem in the past. She said that the psychological effects of her condition worsened in her 40s when she felt that she could not cope anymore. Anxiety was also an issue – this contributed towards the low level of self-confidence.

She said that she did have a good experience with counselling services – nine months of counselling ‘changed my life without question’.

RJ – said that he had felt disappointed by the relatively unrewarding drudgery of treatment. Psoriasis & its treatment could be very discouraging.

MC – said that eczema had always made her self-conscious. She had often ‘struggled to face the world’ but this had lessened somewhat since joining the NES.

MA – said that she never felt low because of the treatment as this was too much a part of her daily routine. She did say however that she had problems with public transport. When on the train, she often felt like everyone was staring at her and this caused feelings of anxiety, this negative experience could affect her for the rest of the day.

Supplementary Question) How has your condition affected your social and intimate relationships?

MC – said that she had often buried herself in work to avoid social interaction.

MW – said that before she was married she used to avoid intimate relationships. This was primarily driven by a sense that no one would be interested in her once they saw her condition on her face without camouflage make-up.

RJ – said that he had never felt affected in this way

MA – said that her condition had made it somewhat more difficult to pursue this type of relationship, but it was by no means impossible.

Dr Sandy McBride

Q6) Could you describe your experience with the NHS and its staff? Please explain as fully as possible, where these occasions took place and the service settings

MA – stated that her experience with the NHS and its staff was a mixed one, it depended completely on who you saw. Some were more empathetic than others. She said that as a child she had felt like she was treated as an object, but since then she had had a number of good experiences.

MC – said that she felt eczema was still treated as a minor condition. When the condition worsens, the patient is often seen as having failed to self-manage their condition.

RJ – Over the 57 years he had had psoriasis he had been treated by GPs and dermatologists. across eight different locations in the UK.

His impression was that things had improved and moved on from the times when patients had to routinely confront long waits, ill-considered treatments and a never ending succession of anonymous doctors, without any continuity of care. He said he was examined once by a dermatologist in the presence of medical students; after the examination the dermatologist turned to his students and said: “Not very interesting that, just another ordinary psoriasis”.

His more recent experiences had been a lot better. When speaking about his local GP he said: *‘I know him, he knows me... and he genuinely seems interested in me’* . This he said could make a huge difference.

However, he was not wholly optimistic about the future quality of care.

MW – said that she had experienced good and bad care but her impression overall was that she had had a good experience with the NHS and its staff.

Supplementary Question) How many doctors have you seen and how many recognised the psychosocial impact of your condition?

MA – said that it depended on who you saw. Her general impression was that interaction with health professionals had got better, however, skin conditions were still trivialised far too often.

‘If you’ve got an empathetic doctor who is not just treating the condition but is also making sure your wellbeing is ok, you have a much better experience overall. And then you feel better about yourself, about your condition, and you actually more likely to look after your condition better as well.’

RJ – said that generic comments such as ‘avoid stress’ were never helpful when discussing the psychosocial impact of one’s condition with a health professional.

He said that patients could face significant psychological problems associated with their condition such as depression but if it was a common issue then *‘why is there virtually no provision for liaison psychiatry in the overwhelming majority of secondary care clinics?’*.

Dr Susannah Baron

Q7) Do you think that GPs and other health professionals know enough about the psychosocial effects of skin diseases?

MA – said she did not think GPs and health professionals knew enough about the psychosocial effects of skin conditions. She said that these types of questions were probably avoided by health professionals because they did not have time to address them. This was probably made worse by the fact that there was not a system in place to deal with these issues once raised e.g. no effective links with psychiatrists and/or counselling services.

Effective communication between GPs and dermatologists were also lacking in her opinion.

...hardly surprising when it came to GPs because they generally did not know enough about '*any aspect of skin disease*'.

MW – said that information on vitiligo had improved and this had helped increase knowledge amongst health professionals. This was partly due to the fact that vitiligo was, for the first time, included in Clinical Knowledge Summaries available to GPs online. In both the diagnosis and management sections it was recommended that the patient's psychosocial problems should be ascertained and some form of counselling offered where necessary.

Supplementary Question) What do you think is the best way to educate health professionals working in the field at a time when the NHS is facing stretched budgets?

MW – said:

'I think it should be considered as part of the management of the skin disease. The psychosocial problem is part of having a skin disease and it should be addressed.'

She also said that she thought a questionnaire might help patients and researchers gather more information on the psychosocial effects of skin disease.

MC – said that there was poor data management surrounding this issue. If this data were to be managed better, then it could be used to further our understanding in this area of dermatology.

RJ – said that he was generally quite sceptical of questionnaires and their usefulness.

Carole Easton

Q8) Were you made aware of any support services that were designed to help you manage the psychosocial effects of your condition?

MA – said that she was never told by any her doctors about support services. However she had been made aware of some through her work with the Ichthyosis Support Group.

MC – said that she had never been told of any such services through her GP.

RJ – said that he had never been made aware of any such services. However he did say things were beginning to move on in this area and there were one or two excellent examples of pathfinder services of which there were representatives in the room.

There were very few examples of first class full-blown integrated services, which was disappointing.

MW – said that her knowledge of such services came from her involvement with the Vitilgo Society and Changing Faces both of which organisations were attempting to provide such services.

Supplementary Question) How do you think these services could help children today?

MA – said that the option should be there for those who needed and wanted it. They needed to be aware however in the first lace that these services existed.

MC – agreed and said that education programmes for families could be one option that might help.

RJ – said that the issue required more thought as this area was very complex (in terms of dealing with children).

MW – said that a number of charities were trying to help in this field but they did not have the funding to do this on a large scale.

Dr Anthony Bewley

Have you ever been asked by your GP or any other health professional to fill in a questionnaire which asked about the psychological and/or social effects of your condition? If no, do you think this would help both you and your GP to manage your skin disease?

MA – said that she had not been asked to fill in a questionnaire by a health professional.

Unless asked ‘you are not necessarily going to volunteer this information’.

She also questioned the effectiveness of the data management and said that questionnaires would have to be managed carefully if services were to benefit from them.

MC – said that she had not been asked by doctors but she had filled in many questionnaires for psychiatrists. She said that these questionnaires were useful in the sense that it helped her understand the real impact that her condition had upon her mental wellbeing.

Again however, she asked what would be done with the results.

RJ – said that he had not been asked by any health professionals to fill in a questionnaire. He reiterated the fact that he was doubtful as to their usefulness. He believed that there was far more to it than that. What was needed was the deployment of better all round clinical skills appropriate to the management of challenging long-term conditions like psoriasis.

MW – said that she had never been given a questionnaire to fill in but she would be interested in seeing this rolled out to highlight the importance of psychological support.

Supplementary Question) Many of my patients that have diabetes or breast cancer feel that the support services are there for them, they know what is available and they know they can access that support when they need it. My belief is that that we just aren't there yet with dermatology. What are your thoughts on this?

MC – said that she agreed entirely with this view.

With diabetes, if something goes wrong the support is there, in dermatology, one would have to wait.

MA – said that ultimately skin disease was perceived to be minor and patients with skin disease had to put up with the lack of understanding and appreciation.

She said that skin diseases were often dismissed in favour of 'more life threatening' conditions. Yet there were in fact a number of potentially life threatening skin diseases.

RJ – said that many people including health professionals lack an understanding of skin diseases. This often led to skin diseases being dismissed as minor problems.

Sir Paul Beresford MP

Q10) Would you say that there has been a greater recognition of the psychosocial effects of your skin disease in the last ten years?

Q11)What would you like to see happen over the next ten years? What improvements do you think are needed most?

The witnesses were asked to provide written submissions to questions 10 and 11 due to time constraints. These are available on request.

**APPG on Skin
December 2012**