Look at me

Integrated care for people with skin conditions

PRELIMINARY CAMPAIGN REPORT
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“Health professionals need to understand the impact of watching helplessly as your appearance changes and also realise the social impacts that you go through not being able to go outdoors or take part in normal social life. It affects way more than just your skin.”

PRELIMINARY CAMPAIGN REPORT

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1 BACKGROUND OF THE CHARITY

Changing Faces is a UK wide charity supporting and representing people and families whose lives are affected by conditions, including skin conditions, marks or scars that alter their appearance. Over the past 20 years Changing Faces has worked with politicians, policy makers and health and social care professionals and commissioners at all levels encouraging the integration of psychosocial care into hospital and clinical settings for people who have disfigurements and their families. We advocate for the development of health care that comprehensively and routinely addresses patients’ physical and psychosocial needs as part of the patient care pathway; the Look at Me campaign is aimed at achieving this in dermatology.

Over one million people in the UK (one in 44) have a significant disfigurement to their hands, body or face – from birth, accident, cancer surgery, skin and eye conditions, from facial paralysis and from medical accidents.

Changing Faces’ work is divided into two areas:

**Changing Lives**
We help individuals lead full and satisfying lives. We give practical and emotional support to adults, children and their families. We offer training, support and advice to professionals in health and education.

- a national Helpline providing advice and information, and signposting people to Changing Faces Practitioners, the Skin Camouflage Service or other agencies
- support from a Changing Faces Practitioner (CFP) (face-to-face, phone, online and in groups) from our London HQ or local Centre
- the Skin Camouflage Service, formerly delivered by the British Red Cross, provided by our volunteers in Changing Faces premises and other locations including NHS hospitals and in local communities
- self-help resources and information for individuals, parents and teachers

**Changing Minds**
We aim to transform public attitudes and promote fair treatment and equal opportunities for all, irrespective of their appearance. People with conditions affecting the way they look are subject to false assumptions, discrimination, prejudice and harassment. We campaign for social change: advocating for more integrated health services; influencing schools and workplaces to create more inclusive environments; and lobbying for anti-discrimination protection and enforcement.

In terms of dermatology, the charity aims to improve the confidence and independence of people with skin disease and offers practical and emotional support and advice through a comprehensive range of Changing Faces services at national and local level.

The Look at Me campaign is supported by an advisory group chaired by Baroness Finlay and includes representatives from the British Association of Dermatology (BAD), the All Party Parliamentary Group on Skin (APPGS), Mind and psychologists. Individuals with skin conditions and their families are involved in the development of the campaign.
2 KEY ISSUES AND EVIDENCE

Skin conditions are extremely common. In a twelve month period, approximately 54% of the UK population experience a skin condition. The most common reasons for seeing a GP are skin infection and eczema.

Many common skin conditions are associated with significant psychosocial problems, which often go unrecognised. Psychological morbidities associated with skin disease include depression and anxiety as well as more low level 'psychological' constructs such as stigma, shame, shame of feeling ashamed, embarrassment, lack of self-confidence, impairments to self-image, anger, guilt, loss, social anxiety and/or avoidance. The visibility of most skin conditions and the response of others often exacerbates a deterioration in quality of life.

Changing Faces client story:

Silvie contacted Changing Faces very distressed, asking for an appointment with the skin camouflage service. She was experiencing a number of health problems including recent onset of a skin condition which dermatologists were having difficulty diagnosing. She had difficulty with her previous GP who she felt ‘didn’t believe her’ when she opened up to him about how things were affecting her emotionally. She increasingly isolated herself and felt ‘closed down’ and afraid to share what was really going on. Her anxieties about her appearance stopped her from going outside, seeing people and going to work. She also struggled to keep appointments. She changed GPs and while she felt much supported by her new GP, she remained reluctant to tell him how her appearance was affecting her life for fear he also would not take her seriously.

Many skin conditions are also long term. Depression is approximately two to three times more common in patients with a chronic physical health problem than in people who have good physical health. Depression occurs in about 20% of people with a chronic physical health problem.

Changing Faces client story:

Alfred has had rosacea on his cheeks for a number of years, despite having treatment it had not improved and he became increasingly depressed. He was not offered any further medical treatment or referral to a dermatology department, but he was offered anti-depressants. He refused to take these due to their side effects, especially the negative physical impact it has on rosacea. He has found it highly embarrassing to speak about his skin disease, especially to people he knows, so getting support has been difficult due to the anxiety he experiences.

4 Magin et al, 2008:1435
5 NICE clinical guideline 91, Depression in adults with a chronic physical health problem Treatment and management, developed by the National Collaborating Centre for Mental Health, issued October 2009, page 4.
Research confirms that despite the vast range of medical skin conditions, the psychosocial concerns of patients who require dermatological care are very similar (Rumsey and Harcourt 2004:85). Commonly, people report feeling self-conscious, conspicuous, angry, rejected, embarrassed or different and they may thus behave in a shy, cautious, aggressive, retreating, evasive or defensive (SCARED) manner.

Changing Faces client story:

Victoria developed melasma about a year ago. She went to see her GP and was then referred to a dermatology department. Victoria was prescribed medication that she had expressed not wanting due to its significant side effects and was also told to wear a hat. She quickly became depressed and highly anxious and preoccupied about her appearance and the impact sun exposure might have on her. She felt she was not given enough information about the condition or its treatment by health professionals to manage her experience. She increasingly avoided going out, found it difficult to go to work and her distress increased.

Evidence on the psychological impacts of some conditions is stronger than others. Alopecia is a condition that can significantly change someone’s appearance. An individual’s reaction to alopecia will vary depending on their own perceptions of body image, self-esteem, coping strategies, personality traits and their social support network.

An example: Psoriasis

The cumulative effect of the psychological, social and physical burden borne by patients with psoriasis is considerable. Indeed the emotional impact of psoriasis is such that as many as 10% of patients, contemplate suicide, especially those of younger age; many more are dissatisfied with their treatment and seek more aggressive therapies. Recognition of the importance of incorporating the psychosocial impact of psoriasis into any holistic assessment of disease severity has led to the development of instruments, which complement measurement of disease extent and severity by assessing its impact on psychosocial functioning and quality of life.

An audit, conducted by the British Association of Dermatologists (BAD) and the Clinical Effectiveness and Evaluation Unit of the Royal College of Physicians Clinical Standards Department showed that record keeping on the severity (physical and psychological) of a patient’s psoriasis was poor. Only 2% of units always recorded a quality of life score in outpatient records and 39% never recorded such a score. Only 40% of units had clinical psychology services available for patients.

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7 British Association of Dermatologists’ guidelines for the management of alopecia areata 2012, A.G. Messenger et al. page 918
8 An Audit of the provision of dermatology services in secondary care in the United Kingdom with a focus on the care of people with psoriasis, commissioned by the BAD and conducted by the British Association of Dermatologists and the Clinical Effectiveness and Evaluation Unit, Royal College of Physicians Clinical Standards Department, January 2008, page 11.
9 An Audit of the provision of dermatology services in secondary care in the United Kingdom with a focus on the care of people with psoriasis, commissioned by the BAD and conducted by the British Association of Dermatologists and the Clinical Effectiveness and Evaluation Unit, Royal College of Physicians Clinical Standards Department, January 2008, page 11.
Changing Faces client story:

Leo has psoriasis on his hands and feet. He is 27 and struggles with self-esteem and social interaction. He has not spoken to his GP about how his psoriasis affects him, as he feels a lack of confidence to do this. He found it easier to contact Changing Faces after seeing something in the media.

An investment in addressing the psychosocial needs of patients with skin conditions is very likely to be cost effective. More expenditure on addressing emotional distress and the most common mental disorders would almost certainly cost the NHS nothing in the longer term and could potentially save money. Early intervention can prevent the development of long term mental illness which is generally more debilitating than most chronic physical conditions. The costs of psychological care are low and recovery rates are high.\(^\text{10}\)

**Changing Faces evidence**

Patient experience is integral to our work and as part of our work for the Look at Me campaign we have, through interviews, focus groups and a survey, gathered evidence from patients with skin disease and their families. The evidence provides insight into the availability and accessibility of services and a better understanding of the care that patients need and would like to receive.

Respondents\(^\text{11}\) had a wide range of skin diseases. The most common ones included eczema, vitiligo, acne, rosacea and birthmarks. The questionnaire was predominantly answered by women but there was a more equal mix in the one to one interviews particularly those conducted in the out patients clinics. The age range was wide but with about half falling within the 25 – 44 years bracket. The length of time people had lived with their condition varied hugely. About a quarter had always had the condition; roughly half had skin disease for longer than five years and just fewer than 15% less than two years.

Care was primarily provided by GPs but other sources included consultants, support groups, family, friends, Changing Faces etc. More than 50% of people found it difficult to find appropriate care with one in four needing to wait for longer than two years and over 50% waiting over six months.

80% of respondents had help or support for their skin disease within the last three years of whom only a third had found what they needed. Only 20% rated it good or very good including the treatment of the condition and the information provided to them.

In terms of how the care was delivered, the three preferred methods were face to face consultations, websites, and leaflets and booklets with at least half of the respondents

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\(^{10}\) *How mental illness loses out in the NHS*, a report by the Centre for Economic Performance’s Mental Health Policy Group, June 2012,

\(^{11}\) The sample included 134 people who participated in a questionnaire (102), one to one interviews (30) and a focus group (2).
highlighting these. Patients wanted to learn more about their condition hear how others have coped and talk to a professional about how they were feeling about the skin disease. They also wanted talk to someone with a similar experience particularly around diagnosis, treatment of the condition, their feelings about their condition and dealing with other people’s reactions to the disease as well as their changed appearance.

In the questionnaire 34 of the 55 who sought help and support for their feelings about their different appearance could not find any support. This was echoed in the one to one interviews too.

The four themes emerging from the research were:

a. **Knowledge and skills of the GP**

“I had repeatedly been misdiagnosed and prescribed the wrong treatment. I was not really listened to or offered a referral”

“Occasionally I’d go to a doctor; I’ve probably seen more than 12 doctors. Quite a few of them would disregard the notes if there were any and just say that it was acne. And I think that was really unhelpful, because it’s like banging your head against a brick wall”.

b. **A slow care pathway**

“Everything just seems to disappear into a big black hole, you get put on a waiting list, and you don’t hear anything else.”

“I got a referral from my GP – it took quite a while, around 12 months –so it was a bit of a wait.”

c. **Lack of joined up care**

“I’ve never been offered any psychological support or put in contact with help groups or organisations.”

“One specialist who took the time to think about my face in a holistic way was amazing.”

“They’re so focused on the ailment, the condition, the disfigurement, they forget that there is someone sitting there getting a bit upset, a bit angry.”

d. **Lack of Information**

“No information from doctors; information is only available from patient support group.”

“The support I got on my patient support group website has been my lifeline. Here I have met women who understand the loneliness and isolation of coping with extensive hair loss.”
3 AIMS OF THE CAMPAIGN

The first phase of our campaign, which focuses on adult skin care in England, aims to ensure that people with a range of skin conditions receive appropriate psychosocial care in addition to medical treatment, integrated into their care pathways. No dermatological consultation can be complete without the psychological component of the disease being addressed.\textsuperscript{12}

Adequate psychosocial care includes:
- Information so that patients can make informed choices
- Advice
- Awareness and sensitivity of all health professionals (immediate support)
- Psychological intervention

Historically, the impact of skin disease has been accorded low priority.\textsuperscript{13} Psychological support is often needed but rarely available.\textsuperscript{14} Lack of availability and access to psychological services however is not the only problem patients with skin condition come across; often psychological needs are not assessed. The recognition of psychodermatological problems requires specific skills and expertise in taking the patients’ psychological history. This is particularly true for patients suffering from depression.

Our campaign objectives are:

1. To influence the development and implementation of quality standards in dermatology to include the provision of psychosocial care

NICE quality standards are a set of specific, concise statements and associated measures that are markers of quality, cost-effective patient care, covering the treatment and prevention of different diseases and conditions. Derived from already available evidence such as NICE guidance and other evidence sources, they are developed independently by NICE, in collaboration with NHS and social care professionals, their partners and service users, and address three dimensions of quality:

- Clinical effectiveness
- Patient safety
- Patient experience

If providers of dermatology care are adhering to quality standards which include psychosocial care, commissioners will be confident that the services they are purchasing are high quality and cost effective. It gives them a legitimate basis to invest in mental health services and training.

The Department of Health (DoH) is undertaking a programme to promote the routine collection and use of information derived from the Patient Reported Outcome Measures (PROMS) completed by patients undergoing selected NHS funded elective procedures. Encouraging the collection of PROMs in dermatology, currently only collected in skin cancer care, could also positively influence the development of psychosocial care for people with skin conditions, as it would highlight the psychosocial needs of patients.

\textsuperscript{12} BAD Working Party Report on Minimum Standards for Psychodermatology Services 2012
\textsuperscript{13} Schofield JK, Grindlay D, William HC. Skin Conditions in the UK: a Health Needs Assessment (2009)
\textsuperscript{14} Royal College of Physicians 2011, Dermatology, last accessed on 17 September 2012: http://www.rcplondon.ac.uk/sites/default/files/dermatology_1.pdf
2. To raise awareness and understanding of the psychosocial impact of disfiguring skin conditions amongst health and social care professionals and commissioners in the area of dermatology

Practitioners tend to view skin conditions primarily in terms of medical severity as opposed to looking at the impact on patients’ quality of life.\(^{15}\) Even when there is availability of psychosocial support, there is still a lack of responsiveness amongst health professionals; patients report having difficulty being referred, as health professionals do not identify psychosocial needs or do not take them seriously and patients feel reluctant to tell practitioners about their psychosocial concerns.

Standards of dermatology training for non-specialist health professionals, especially for pharmacists and doctors and nurses in primary care, are inadequate.\(^ {16}\) Most patients (93.9\%) are treated by their GPs, the ‘gatekeepers’ to more specialised dermatological care and they too need to have an understanding of the psychosocial effects of skin disease.

3. To raise awareness amongst people with skin conditions to understand what service they should be able to expect from their health and social care professionals.

Referral to a mental health professional is beneficial for some skin patients; psychological interventions can actually improve physical symptoms.\(^ {17}\) Patients who are not aware of the benefits of psychological support and patients who may be reluctant as a result of the stigma attached to ill mental health, are unlikely to be access services. Understanding of the benefits of psychosocial intervention, the effects on the skin disease and the availability of services is crucial for people with skin conditions; it empowers them to be advocates for their own care.

Patients need high quality and up to date information on services to assist them in making informed choices. Psychosocial services need to be promoted by health professionals in a way which helps patients overcome their reluctance to ask for help, and they need to be welcomed by patients, similar to physical care.

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\(^{17}\) British Journal of Dermatology, A Meta-Analysis of the Effectiveness of Psychological Interventions for Adults with Skin Conditions, A.C. Lavda, T.L. Webb, A.R. Thompson. The Department of Psychology, University of Sheffield, June 2012.
4 ACTIVITIES, STAKEHOLDERS AND TARGET AUDIENCES

The key target audience for this campaign are GPs in England, who will, from April 2013, be responsible for designing local health services in England and see the majority of patients with skin conditions. GPs, in the capacity of non-specialised commissioners, will sit on Clinical Commissioning Groups (CCGs) and are expected to initiate and maintain dialogue with a variety of groups to ensure that commissioning decisions are not made in isolation either from the patients and public, local authorities or other health and care professionals. Commissioners need to take account of a wide range of factors to make informed decisions. These include national guidance and priorities, clinical evidence, ethical frameworks, local needs, access to services, service quality and outcomes. All GP practices will have to belong to a Clinical Commissioning Group; Changing Faces aims to influence local decision making as well as regional and national decision making by the National Commissioning Board.

Other priority target audiences are politicians, dermatologists, dermatology nurses, mental health professionals, specialised commissioners and people with skin conditions and their families.

Each of the target audiences requires different campaigning activities; audiences need to be targeted with tailored communications, a general message will not be heard and we want our audiences to take a variety of actions. This report is the start of targeted messaging that has the overall, long term aim of achieving better quality of life for people with skin conditions. In addition, a final campaign report will be produced in 2013 which will present clear evidence, good practice examples, service models and references to other reports on psycho dermatology and the psychological effects of skin conditions by the BAD and the APPGS.

People or organisations that are affected by this issue or can have an influencing role are multiple. We are aiming to work closely together with other skin charities and support groups, mental health and disability charities and all relevant professional bodies.

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5 GOOD PRACTICE EXAMPLES

As Changing Faces supports people whose lives are affected by all conditions, marks or scars that alter their appearance, we have strong examples of how holistic care can be delivered effectively in other specialties than dermatology. Although the conditions and specialties are very different, the key issues are similar; more attention must be given to the psychosocial needs of people with a visible difference and care needs to be provided holistically. Changing Faces Practitioners, the Outlook service in Bristol and developments in burns care and cleft lip and palate care are considered to be good examples:

Changing Faces Practitioners (CFPs)
Changing Faces Practitioners are specialists working with adults, children, families and schools. Through advice, information and practical and emotional support, people with disfigurements, including people with skin conditions, are helped to build confidence and develop social skills so that they can manage the psychosocial impact of their condition. They apply the FACES package which blends information (such as our self-help guides), practical advice, skin camouflage, social skills training and emotional support. It is always tailored to each individual’s needs after assessment by one of the Changing Faces’ Practitioners. In future, CFPs can be based in the community as well as in hospitals.

Outlook Bristol
Outlook is an NHS psychological support service, originally funded by Changing Faces and later converted into a statutory service, for anyone affected by a disfigurement or visible difference from any cause. Outlook offers support and help for people of all ages who are coming to terms with a different or unusual appearance or a disfigurement. It is a friendly, supportive confidential service for children, adolescents and adults. The team aims to help improve the day-to-day experience of living with a different appearance, providing practical psychological support with difficulties including:

- Finding positive ways of dealing with other people’s reactions, for example questions, staring, teasing, bullying or discrimination
- Coping with self-consciousness related to appearance and improving confidence and self-esteem, for example about social situations or school / work
- Coping with anxiety about starting or changing a job or school or about intimacy in a current or future relationship
- Psychological preparation for surgery or other medical treatments and support with making decisions about treatments

Burns care
In recent years, there have been significant improvements in the provision of psychosocial support to burns patients. There is greater awareness of the psychosocial impact of burns both by the burns professionals and their teams. Changing Faces and the London and South East Burn Network have worked closely to develop a teaching pack so all staff in burns units and centres can receive training appropriate to their role in understanding the psychosocial aspect of living with burns. There is specialist dedicated psychologist support in the specialist burn services in England and Wales, often as part of the core multi-disciplinary (MDT) teams. The national framework has integrated psychosocial care in the care pathways and there is a commitment to improving skills and confidence across the whole care team to assess and respond to patients’ psychosocial needs. Moreover, there is increased capacity and resource to meet patients’ needs during their inpatient care at specialist burn care services.

19 FACES stands for Finding out, Attitude building, Coping with feelings, Exchanging and Social skills training
Changing Faces has been actively engaged in advocating for the best outcomes for patients with burn injuries for many years including their psychological and social rehabilitation. We have worked with the clinicians and their teams, and commissioners to heighten their awareness of the psychosocial needs of patients and their families.

Cleft Lip and/or Palate Care at Addenbrooke’s, Cambridge
When a baby is diagnosed with a cleft condition there is an immediate referral to the Cleft Team. All members of this multi-disciplinary team have a shared responsibility to recognise and respond to psychosocial needs of patients and parents from day one right the way through the child’s development up to the age of 20.

Anxieties and fears about hospital procedures are common and it is the job of the clinical psychologist to support children and young people when the Cleft Team asks for help. Advice for parents and behavioural assessment and therapy for children can be invaluable. The psychologist also assesses other aspects of the child’s psychosocial wellbeing in education settings, public places and making friends.
6 WHAT TO EXPECT FROM THE FINAL REPORT

A final campaign report will be published in 2013 which will include further academic and organisational evidence, an overview of good and bad practice in England and recommendations on care pathways and how to provide the best holistic care in dermatology.

7 CALL FOR EVIDENCE

In order to get a more comprehensive overview of good and bad practice in England, we are asking all people with a skin disease to tell us about their experience of NHS healthcare. The strongest message that we can send is a message that comes straight from the people we are here to support. It shows the need for improvement, the need for better psychosocial health for people with skin conditions through better and more integrated care.

To gather as much evidence as possible, we are also aiming to work closely together with patient support groups and skin related charities as well as the British Association of Dermatologists (BAD), the British Dermatological Nursing Group (BDNG), the Primary Care Dermatology Society, the Royal College of General Practitioners and various other professional bodies.

Please contact us if you have or have had a skin condition and want to share your story or if your organisation would like to contribute views or evidence. Send an email to Henrietta Spalding, henriettas@changingfaces.org.uk or contact her on 020 7391 9287.

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