



The information needs of patients with disfiguring conditions - *a Healing Foundation Project*

Disfigurement can affect people of all ages and backgrounds. Many people with a condition that affects their appearance need help, support and information to enable them to manage the physical, psychological and practical consequences.

A three year study seeks to examine these needs and answer some of the questions regarding the type of information patients with disfiguring conditions want and currently receive.

Finding out more

Information is vital to patients. It helps them make choices about their healthcare, cope better with their condition and its consequences, and form realistic expectations about the outcomes of treatment.

People with disfiguring conditions are treated by a multitude of health professionals including plastic, orthopaedic and maxillofacial surgeons, dermatologists, oncologists, psychologists, occupational and speech therapists. Support groups and charitable organisations exist to help patients and raise awareness of various conditions, and commercial companies offer information and advice on a wide range of subjects from prosthetics to skin camouflage products. **How useful are all these sources of information to patients?** How reliable is the information? Is it easy to understand? What is the best medium, and who is the best person, to give patients the information they need?

Adjusting to the outside world

Our appearance affects the way we, and others, see ourselves. If that self-image is altered by disfigurement, people often experience considerable emotional distress in addition to that caused by any impact on their physical well-being.

How easy is it for patients to find information to support psychological adjustment? Does what is currently available help them deal with the effect on their personal relationships, work and social life? Does it help them to cope with the reactions of others to their appearance?

The Healing Foundation Patient Information project

The study

- a three year research programme begun in September 2003
- designed and managed by the Healing Foundation
- conducted by the Picker Institute, Oxford
- funded by the GUS Charitable Trust

Aims

- to investigate the information needs of patients with conditions that affect their appearance by:
 - assessing the need for information
 - providing an overview of what is currently provided
 - highlighting gaps and weaknesses
 - making recommendations for how things can be improved

Methods

- a review of previous research
- evaluation of the quality of existing information materials
- in-depth discussions with patients, healthcare professionals and others
- a wider examination of the issue by means of a survey

First report

The first report describes the findings from the review of previous research and in-depth interviews and discussions with patients, health professionals and representatives of the voluntary sector. Our work to date has provided insights into the information patients currently receive and the complexities of the information exchange between patients and clinicians.



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Key findings from the first report

General and specific information

"I can remember thinking I wonder if he'll be able to sing, silly things like that."

(Parent of a child born with a cleft lip and palate)

A wide range of information needs are common to all types of patients. These include details about diagnosis, treatment options, side effects, self-care and coping skills. In addition patients want details relevant to their specific condition, for example, genetic information for the parents of children affected by congenital disorders, the latest developments in prosthetics for amputees, and scar care for patients with burn injuries.

Due to the long-term nature of most of their conditions several patients discussed how their needs have changed over time as they moved from treatment through to rehabilitation and self-care.

Appearance

"When they are first born, that is the main worry...what are they going to look like and if somebody came along and explained that to you...that's probably what you'd be more interested in."

(Parent of a child born with a cleft lip and palate)

Many patients expressed a need for honest indications of how they were going to look following surgery or as scars healed. It was generally felt that the media attention given to cosmetic surgery can lead to unrealistic expectations. In particular, burns patients mentioned the importance of 'before and after' photographs to help them visualise how their scars might heal in the future.

Supporting psychological readjustment

"If someone had given me 10 minutes and said 'There's a process that you're going to go through...' for some professional to actually acknowledge this ghastly inheritance with facial disfigurement and that we withdraw within ourselves and that is part of the process and is natural."

(Head and neck cancer patient)

"It's very, very important the way that you are told information."

(Parent of a child with a craniofacial condition)

Patients and carers in all our discussion groups spoke about the psychological and emotional impact of their own or their child's disfigurement. Parents had to cope with feelings of guilt and anxiety, whilst many trauma victims expressed both anger and frustration. Our review of studies on the psychological consequences of altered appearance found several evaluations of strategies for dealing with staring, teasing and bullying in everyday life.

Meeting information needs

"'Well will I be able to eat?'and he just said 'Yes you'll be able to eat' and I was happy in that knowledge but the actual reality of it was that I couldn't."

(Head and neck cancer patient)

Some patients were very happy with the support they had received but many more had experienced shortcomings, particularly in relation to their psychosocial needs and the more unpleasant consequences of surgery. Our study and the review of previous studies suggests that patients require more details about their condition and treatment options than they are usually offered.

The process of information giving

It emerged from our research that how and when information is given to patients is as important as its content. Patients still regard their consultants as the main source of information, but a significant number reported they were unhappy with their communication skills. Recent years have seen the arrival of clinical nurse specialists. Many of the patients and parents we interviewed found them a valuable resource. They tend to be more accessible, have more time and see themselves as more effective communicators than doctors.

Key Facts

An estimated 400,000 people in the UK have a disfiguring condition that seriously affects their quality of life¹

The reasons for disfigurement range from congenital disorders to accidents and disease

There were 4,400 new cases of mouth cancer in the UK in 2001²

One in every 600-700 children in the UK is born with a cleft lip and/or palate³

Over 5,000 amputees are referred to UK prosthetic centres every year⁴

1 (Office of Population 1988); 2 Cancer Research UK; 3 (Cleft Lip and Palate Association); 4 (National Amputee Statistical Database)



Producing NHS information materials

"We haven't any support either so you write it, you design it yourself. The communications department may help a bit but it is the time thing."

(Dermatology professional)

The increasing number of both national and individual hospital guidelines on the production of patient information demonstrates the growing importance being given to this aspect of healthcare at a policy level. Despite the best intentions of many of the health professionals we spoke to, they accepted that the actual quality of materials varies greatly. Although a few were proud of the work they were doing in this area, more professionals felt that a lack of time and resources prevented them from doing as much as they would like.

The voluntary sector

"I don't think we've looked anywhere else because we haven't felt the need once we belonged to our local support group."

(Head and neck cancer patient)

Both patients and health professionals used information produced by charities and patient organisations. In most cases this was to supplement information provided by the NHS, but in a few instances it seemed that it was used to plug a gap, particularly regarding psycho-social concerns. Patients and parents generally spoke very positively about the support they received from these organisations, but a few expressed reservations about the quality and appropriateness of some of the material they provide.

The internet

"With the invention of the internet, you type in one word and it gives you everything you want."

(Parent of a child with cleft lip and palate)

"If someone's been on the internet, my heart sinks."

(Plastics professional)

The internet is now a major source of health information and the vast majority of patients and parents we spoke to had used it to search for details on their own or their child's condition at some point. Professionals also recognised the power of the internet, albeit reluctantly in some cases. Concerns were expressed about the credibility of the information found there, but generally patients felt able to make their own judgements on its reliability.

The media

Concerns were also expressed about the reliability of the media as a source of health information. Both patients and professionals were aware that sensationalism and misinformation could lead to unrealistic expectations. On the other hand, several television documentaries have been broadcast on the subject of disfigurement during the course of this study and many patients thought that when sensitively produced, such programmes can increase social awareness and promote public understanding.

Peer support

Meeting and talking with those in a similar situation was highly valued by virtually all patients and is seen as being as important as the information provided by clinicians. As well as being able to share information, peer support provides an opportunity to gain reassurance, emotional support and practical advice. It is usually organised through the voluntary sector, but some health professionals described ways in which they arrange contact within the healthcare setting. There were a few patients who preferred to cope on their own and found support groups patronising.

"People who have had a similar experience...know what they are talking about...and they've often got very practical, helpful advice."

(Burns survivor)

"It has to be presented in the right fashion...not sensationalist or gruesome...the only thing you wantis more understanding."

(Craniofacial patient)

The kinds of patients taking part in our research

In 1998 Edward received 80% burns in a gas explosion while on holiday in Spain. He still continues to have skin grafts and suffers severe nerve damage pain. Like many burns patients, he was not in a position to ask questions in the early stages of his treatment, but now he researches new possibilities assiduously and plays an active role in decision-making about his care.

Hannah has a little boy with a craniofacial condition. She does not want to spend her time looking for information about Apert's Syndrome on the internet. Her comfort and support comes from her relationship with another mother in the same situation. They give each other a sense of normality.

Information seeking behaviour

"Gather as much information as you can, ...and get counselling, don't be ashamed, ask for help, if you don't get help from one doctor, go to another, until you are actually satisfied."

(Vitiligo patient)

"I kept on being offered sources of information. I wasn't really that interested."

(Head and neck cancer patient)

There is a growing trend towards better informed patients who expect to play a greater role in making decisions about their own healthcare. This was reflected in the discussion groups, although the patients who took part probably represent those who are more actively engaged. Some participants thought too much information at the wrong time might actually increase rather than reduce their anxiety while others deliberately chose to limit how much they accessed. Professionals appreciated the skill involved in judging how much information to offer and when.

What happens next?

- In spring 2006, a postal survey will be mailed to patients living with a range of disfiguring conditions to provide a wider assessment of the information needs of this patient group.
- The results of the survey and the evaluation of information materials, together with a review of best practice and recommendations for the future, will be published in the final report of the Patient Information Project.

Where can I find out more?

Copies of the full first report can be downloaded from the following websites:

The Healing Foundation: www.thehealingfoundation.org Picker Institute Europe: www.pickereurope.org

Picker Institute Europe

We are an independent, not for profit research and development institute with charitable status.

We work with patients, professionals and policy makers to promote understanding of the patient's perspective at all levels of healthcare policy and practice.

We undertake a unique combination of research, development and policy activities which together work to make patients' views count.

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The Healing Foundation

We are a national fundraising charity championing the cause of people living with disfigurement and visible loss of function, by funding research into pioneering surgical and psychological healing techniques. Through research, we also raise awareness about the cause and provide information about the sources of support.

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