*ABC of burns***When we leave hospital: a patient's perspective of burn injury**

Amy Acton

At the age of 18, I thought I had the best summer job possible, working outside at the local marina, with the prospect of going to college in a few months to become a nurse. In an instant everything changed. While moving a boat on a trailer, a group of us sustained electrical injuries when the mast hit a high tension power line. I found myself fighting for my life in a burns centre and mourning the loss of a friend. The physical healing was gruelling and at times overwhelming for me and my family, and the medical team was a great support for me. However, this article focuses on the problems I faced once I left the hospital, two and a half months later, because that was toughest part of my journey.

My comments are both personal and from the perspective of having been a burn nurse for over 13 years. It is a shared story of healing the emotional scars of burn injuries because I have learnt so much from others. One such person is Barbara Kammerer Quayle, a fellow burn survivor and colleague I met after I became a burn nurse. She taught me how healthcare professionals could make a difference for survivors struggling to regain a place in their family and society. Many of the strategies I discuss are her life's work and are used with her permission. For some burn survivors these strategies are natural responses, but for others they have to be learnt and practised.

Facing the world

While in the secure cocoon of the burn centre, I received extraordinary social support and acceptance from staff. After my discharge and return to my community, however, I felt surprised, shocked, and sometimes completely overwhelmed as I realised I would face the curious stares of strangers. I had remained focused on my physical healing and had never thought about how my burns would affect my life long term. Addressing this issue with patients and families must become part of the discharge process from burns centres.

Before my burn injury, I passed through shops, restaurants, churches, and social occasions with minimal interest from others. Now, wearing splints and pressure garments, I found all of that had changed. I was not prepared for this and had no idea of how to cope with people's reactions. It was not until almost two years later that I felt comfortable in social settings, as I learnt to love my body again and realised that I could make a big difference to how others responded by my attitude.

Attitudes about appearance

From childhood onward, we develop our attitudes about appearance. We possess a complex set of beliefs about what appearance means in our life. These beliefs are the result of our thoughts and influences by parents, teachers, friends, magazines, films, and television.

When my appearance was altered by my burns it threatened my existing thoughts and beliefs about my appearance and who I was. Over time, I and many other burn survivors do accept the alteration in our appearance, and incorporate the changes into a healthy body image, and go on to live successful lives. This takes time, support, self love, and learning new behavioural skills. For some, it is a lifelong struggle.

Pressure garments stimulate reactions such as stares and questions

Staring: a fact of life

Staring is part of human nature. Heads turn to look at teenagers with tattoos and body piercing, people with hearing impairments signing, those using wheelchairs. It is a fact of life that looking different gets attention. Staring has power and meaning only to the degree to which we give it meaning and power over our lives.

I gradually found that most people stare because they are unfamiliar with burn injuries and feel compassion and concern. Others are simply curious. A few stare because they are overwhelmed by such a traumatic injury, and the fewest stare because they are rude.

What we see depends on what we are looking for

The way we choose to interpret and perceive stares will influence our ability to cope with them. If we focus our attention on staring and perceive stares as evil and threatening, then that will be our experience. If, however, we diminish the importance of staring and interpret stares as a mild inconvenience, that will be our experience. Our interpretations and perceptions either defeat or enhance our social success.

Faulty assumptions

In his book *The Body Image Workbook* Thomas Cash states that it is flawed thinking to assume that, simply because they notice you, people will dislike you: "friendliness, kindness, and conversational skills" are "more influential than whatever might be different about your looks." Instead, the truth is that "you are the one noticing what you don't like about your appearance." Other people usually do not care because they are thinking about other things.

In the first months after my burn injury, I wore clothing to hide my injuries and continually looked to see if people were "looking" at me. People staring and seeing my scars became the focus of my attention, and I felt uncomfortable in social settings. I spent much of my energy worrying what others thought. Many burn survivors have reported the same behaviour.

Cash also points out that "first impressions don't always last" and "our initial reactions to someone's appearance are not frozen forever in our minds." A person may focus on a burn survivor's appearance initially. I consider this pretty normal. When I meet another burn survivor for the first time, I often take a few minutes to "get used to" the new and unique skin patterns I am seeing. After we have established a relationship, however, the burns become less important, and personal traits such as intelligence, humour, integrity, and sensitivity are the most defining characteristics. Often I forget exactly where a person's burns are located—which side of the face, which hand, etc. By strengthening our social skills, we can overcome the challenge of looking "different."

So what do I do?

Barbara Quayle has developed some simple strategies to help those with physical differences respond in a positive way to questions and staring. By practising these strategies, many burn survivors have become more comfortable in social settings. These techniques are easily taught to patients before discharge from hospital, and they should be part of the care plan for all burn survivors.

"STEPS"

If you find yourself being stared at, Barbara suggests standing up straight, looking directly into the person's eyes, smiling, and, with a friendly tone of voice, saying "Hi, how are you doing?" or "Hi, how's it going?" or even "Hi, great day, isn't it?" Looking at

Reasons why people stare at burn survivors

**"You are the one noticing
what You
don't like
about your appearance."**

**"If you act like a
victim, people will
treat you like a victim."**

B Quayle

"Hi, how's it going?"
**"Hi how are
YOU doing?"**
**"Hi great day,
isn't it?"**

and speaking to the person shows social awareness and self confidence. When you project confidence and poise the person staring usually responds in a friendly manner, looks away, and goes on with his or her business. When a stare triggers a comfortable and confident response, the person is sometimes surprised and often a little embarrassed about staring. Remember, you are in control, not the person staring. Become conscious of your own behaviour.

If eye contact, smiling, and speaking seem like too much at first, simply "look 'em in the eye" and smile. Energy and warmth radiate from faces wearing smiles. People who smile at others have advantages in forming relationships because a smile often dispels the fear and apprehension of strangers. In new situations a smile can break barriers or end prejudicial judgments. It sends a message of being approachable and at ease. A smile also diminishes the visual intensity of scarring and skin discoloration. The STEPS acronym will help you remember to take control and not "act like a victim."

Another alternative is simply to ignore the person staring and go about your business. Sometimes this may be preferable if you are tired or not bothered by the stare. I never advocate reacting to staring with an angry response. Anger at others often hurts most the person who is angry. When you respond with anger it is usually out of fear and says more about you than the person staring. There will be times when you or a protective family member want to lash out verbally at someone staring, but being abusive does not reflect well on you or your family and may leave you feeling frustrated, resentful, and bitter.

"Rehearse your responses"

Another helpful technique that Barbara teaches is to be prepared for people's questions. Often burn survivors and their families feel awkward, uncomfortable, angry, or embarrassed when strangers ask questions about their burns. If survivors can develop a two or three sentence response to such questions and then practise this in privacy with family and healthcare professionals, they will have greater confidence in new social situations.

It first must be a conscious effort. Then, as you "rehearse your responses," you find it becomes second nature, and eventually you become proud of your positive attitude and how you handle social situations.

Healthcare professionals can help

It is the responsibility of healthcare professionals to discuss staring with burn survivors and their families before discharge. They need to know that some people will stare, ask questions; and helping them to practise specific strategies to use in public and in social situations can only assist them in making the successful transformation to a person who thrives after surviving a burn injury.

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The ABC of burns is edited by Shehan Hettiaratchy, specialist registrar in plastic and reconstructive surgery, Pan-Thames Training Scheme, London; Remo Papini, consultant and clinical lead in burns, West Midlands Regional Burn Unit, Selly Oak University Hospital, Birmingham; and Peter Dziewulski, consultant burns and plastic surgeon, St Andrews Centre for Plastic Surgery and Burns, Broomfield Hospital, Chelmsford. The series will be published as a book in the autumn.

Competing interests: AA is executive director of the Phoenix Society for Burn Survivors. See first article for series editors' details.

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STEPS[©]

BE SURE TO:

Use **self talk** (I can handle this confidently)

Speak in a friendly **tone of voice**

Look 'em in the **eye**

Posture - stand up straight

Wear a **smile**

Rehearse Your Responses

"I was burnt in a car crash a few years ago. I am doing better now. Thanks for your concern." The ending brings closure to the conversation

To learn more about support for burn survivors and to obtain articles by Barbara Kammerer Quayle and the Phoenix Society, visit the society's website at www.phoenix-society.org

Further reading

- Cash TF. *The body image workbook*. Oakland CA: New Harbinger Publications, 1997
- Quayle BK. When people stare. *Burn Support News* 2001;2(summer).

The picture of a pressure garment is used with permission of Gottfried Medical.