

CASE NOTES

Burns Emergency and Emotional Support ~ A Self-Help Group

B.E.E.S., Burns Emergency and Emotional Support, is a self-help group for people who have been burned and their families. I am a social worker employed in the Burns Research Unit at the Royal Children's Hospital in Melbourne, and I was involved in starting BEES and am currently a committee member.

To briefly explain the concept of self-help, I would like to quote from an article by David Robinson in the British Journal of Hospital Medicine, ¹, in which he says

" mutual self-help is, of course, as old as human history. It certainly does not need sociologists, psychiatrists, historians, or priests to draw our attention to the simple fact that people who share a common problem might possibly have something to offer each other. Men have always banded together to solve their common difficulties and promote their mutual interests, in family networks, clans, tribes, guilds, professions, trade unions, friendly societies, and clubs and on street corners. One of the ways in which this basic feature of human life is being expressed in the latter part of the 20th century is through self-help groups."

BEES was formed following a feasibility study which was undertaken by myself and two social work students in 1981, and which established that there was a place for a self-help group in the rehabilitation of burns victims. A small group of parents of children who had been burned started meeting together in June 1981 and the group developed from there.

MUTUAL HELP AND COMMUNITY EDUCATION

BEES is a small but enthusiastic group who offer support to people who have been burned and their families, and who also aim to educate the community to be more aware, understanding and accepting of people who have disfiguring burns scars. People who have experienced problems following a burn injury can offer real understanding to others in a similar situation.

BEES provides an opportunity to both gain and give mutual support and also helps people to realize that there are many people who have been burned and they are, therefore, not really unusual. BEES has developed along the lines elucidated by David Robinson when he

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describes the key element of self-help groups as follows:

"It is this understanding based on common experience that produces the necessary common bond of mutual interest and common desire to do something about the problem. The basic ingredient of this doing something is collectively helping oneself to help others is to help yourself."²

The people in BEES feel that many of the problems faced by people with burns are caused by the ignorance and insensitivity of others. So we are trying to educate the community — by television coverage, by magazine and newspaper coverage and by distribution of pamphlets. Our next project is the making of a video which will depict some of the emotional aspects of burn injuries but will emphasize that these are normal people who are able to lead a normal life if allowed to do so.

NO DISABILITY

People who have been burned rarely have any lasting physical disability, yet they are constantly confronted by a community that expects them to be disabled in some way. Teachers ask parents to describe their child's handicap or disability; employers assume they are mentally disabled or impaired; people shout at them as though they are deaf. The main disability most burned people have is the ignorance and to some extent

fear of unsympathetic and insensitive people in the community. There is a "social disability". This understanding has emerged from the people within the group.

BEES members tell stories of being followed around the supermarket and stared at by other curious people who for some reason assume that they cannot hear, and discuss between themselves what must have happened; or of the woman that approached a 7 year old child whose face had been burned and without speaking to the child ran her fingers over and around her face; or the people who were standing just behind a mother and her child outside a large department store in Melbourne and said loudly to each other — "If I had a child like that I wouldn't bring her out — people shouldn't bring children like that out into the public"; or a teenager who is called "French fries" or "barbeque chook"; or an 8 year old who is called "spastic". There are also more subtle prejudices — such as employers who feel that despite better qualifications a person who has been burned would be a more 'risky' employ — that they must be accident prone, or liable to want time off work, and so on. Again the prejudice is in the mind of the observer.

WHO IS BEES RELEVANT TO?

A self-help group is not relevant to everyone who has been burned, but it certainly is relevant to some.

We deliberately planned to extend our membership gradually, and in doing so we have learned more about the time at which BEES may be relevant.

We have found that when children with major burns have been discharged from hospital for a considerable time — say a year or so — and have been living with their disfigurement, they are more likely to be interested in meeting together with others in a similar situation. When a child returns home after his initial hospitalization, he and his family are usually relieved to be back home and away from the hospital. They are keen to resume their former way of life and often try to deny that the accident will affect their own or their child's life in the future. However as contact with the hospital lessens — out-patient appointments become more infrequent — they become more alone in coping with problems that arise, as burn injuries are suffic-

iently infrequent that most people do not know others in their own social circle who have been burned. With the passage of time they have also been forced to realize that many scars are permanent. This is the stage when a self-help group such as BEES can be helpful.

We believe that participating in BEES enables people to acknowledge that they have this injury, and enables them to adapt this knowledge to their own lifestyle in a helpful and healthy way. The people who belong to BEES are not people weighed down and preoccupied by their own problems — they are people who are able to care for newcomers and look beyond themselves to the needs of all burned people.

Like most self-help groups, BEES emphasizes for members the importance of living independent satisfying lives in the normal community; it does not encourage withdrawal from the wider community.

THE PLACE OF BEES IN THE RANGE OF SERVICES

A self-help group does not replace any of the services provided by the hospital; it is an additional service outside the hospital, which does not pose a threat to any of the professional services involved in earlier treatment.

Self-help is different from other professional forms of help in that it removes from the person with the problem the onus of asking for help no appointments are made; help is given with pleasure when requested and is offered spontaneously even when not requested. The help is given by people who have also become or may become friends and this help arises out of personal concern.

So the service provided by BEES is of a secondary rather than a primary nature; its service is supportive and complementary. Its focus is rehabilitation of the individual in the broad sense of promoting the person's ability to once again lead an active and fulfilling life, unimpeded by emotional difficulties, stigma and discrimination.

A recently held family weekend camp provided a unique setting for sharing of experiences that are related to being burned. BEES aims to promote this type of sharing and support by a range of formal and informal activities.

NEW DIRECTIONS

We are aware of the need for some provision to be made for teenagers who have been burned. Teenage years are often turbulent and troubled; there is emphasis on the desire to be the same as one's peers, but a teenager with disfiguring burns scars can find this an im-

possible goal, and these years can be lonely and difficult. We are planning to organize a camp for teenagers. The Little People's Association recently organized a camp in the snow for teenagers — we hope to also have a good "theme".

We are establishing a sponsorship system, as does Alcoholics Anonymous. Each new member will get a sponsor who will act as a liaison and a friend.

We will continue to hold regular monthly meetings. This is seen as important as it provides the opportunity for both old and new members to make contact with each other, to build relationships, and develop a sense of belonging to the group.

A recent development has been the formation of a Social Committee which plans to organize a monthly social activity for members. This sort of activity promotes the development of informal friendships and means that BEES becomes part of people's ordinary lives.

CONCLUSION

I would like to conclude by quoting Dr. Alfred Katz who when addressing an Australian forum on self-help groups said:

"there is a wide possibility for mutual aid and mutual co-operating between professionals and self-help groups, but this demands mutual respect and humility on both sides. Each has something to offer, each has something to learn from the other; neither should seek to dominate the other".³

And finally, a surgeon can do remarkable things to relieve disfigurement. He needs help to restore the person's smile and replace a child's laughter. That is the work of BEES.

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