

HOW AMPUTEES FEEL ABOUT AMPUTATION¹

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To obtain the views expressed in this report, four amputees were interviewed in depth. Two were doctors, one was a psychiatrist, and one was a prosthetist. One of the most interesting things to come out of the interviews was that, though their skills, interests, and education levels were different, the four amputees gave quite consistent responses to the questions asked. They tended to emphasize similar lines of thought, and offered quite similar solutions to the problems discussed.

FEELINGS ABOUT AMPUTATION

When amputation offers some powerful advantage, such as saving life and reducing disfigurement and pain or some other objectionable factor, its acceptance by the patient is relatively easy. When loss is due to an accident, the nature or intensity of feelings depends upon the circumstances. A bitterness is aroused that is hard to reconcile when the reason is another's negligence. If due to one's own negligence, remorse and guilt are experienced. If another was unwittingly involved, the guilt may be stronger.

One of the amputees interviewed indicated that anger rather than panic struck him when he lost his leg under a railway car on which he was working. Although such an experience would be imagined to be painful, in fact it was not especially painful, although effects of the environment at the time and cramps from shock caused discomfort.

Under circumstances which lead to a deprivation of function, the impact of amputation is very great and persists for a long time. One man indi-

cated that, although he had been well rehabilitated, the implications resulting from the trauma took three years to overcome. Conversely, though physically deprived of function, the amputees indicated that they felt no different after amputation than before; that is, they were the same person as always. None felt that psychiatric input would have helped him. Of paramount importance, however, was the need for psychological insight on the part of the people treating them, including the doctor, therapists, prosthetists, and nurses. We hear of the importance of body image. The amputees who discussed these matters indicated the peculiarity of noting that a part of their bodies was missing. Eventually this too becomes accepted and the person may eventually reach the stage where to look whole again would seem strange, change in appearance being the important factor. Meanwhile, reduced function as evidenced by such factors as reduced capacity to keep up, limping, noises from a prosthesis, or the need to use crutches, imposes feelings of inferiority.

Given full attention, an amputee can be rehabilitated by a well-coordinated team so that the functional return and acceptance of amputation are optimal for that patient. Who can say that every vestige of psychological trauma can be erased no matter how sound the man? But it can be said with certainty that bungling the rehabilitation process through poor coordination of team members, deficient understanding or inadequate prosthetic devices will reduce prospects for success, and have a long-term effect, no matter what is done to recoup. This doesn't mean that patients need everything laid out for them. On the contrary, the amputees said that they derived satisfaction from overcoming the obstacles of disability through rehabilitation and adaptation. What they wanted was support. This support should be in the form of usable information and quite explicit instructions based on facts which they can readily grasp and follow.

The amputees indicated that they began to worry about jobs and families as soon as they were conscious. They wanted vocational coun-

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selling early to allay concerns, or at least to give them something to work with. They wanted this counseling to be realistic, take into account their reduced functional capacities, and prepare them for a changed job or retraining that would save them from future stress.

INFORMATION

The plea for useful and reliable information was strong. Many questions arose which were handled variably by the treatment staff. Most important was to have a simple, realistic appraisal of their situation. Sometimes events leading up to amputation are not clear. How did it all happen? What of their families, social associates, colleagues at work, etc.? And a fundamental question among the young is—"Will I be sexually acceptable?" This issue is seldom raised, though it is almost the first thing of concern to younger amputees. Young males frequently set out with great courage to find out.

Misinformation from ill-informed but well-meaning staff members was a strong irritant. When the information was discovered to be phony, ill-conceived, or exaggerated, there was great resentment. Those involved in the treatment of amputees should have a fund of common information that will help to ensure consistency of management from beginning to end. Further, the patients with whom these matters were discussed wanted to be in on what was being planned, not just be recipients of what was handed out. The clinic team must include the patient in its deliberations to the fullest extent possible. At least the results of clinical thinking should be summarized and presented to him in a way that informs him that his care has been thought out, and that the decisions made are considered appropriate. Further, this information should be presented so that he can amend plans in ways that touch on his own specific requirements.

Besides information about himself and relationships with family and community, work situation and recreation, he wants information about the prosthesis he will receive. He wants to know how much it costs, how long it will last, how strong it is, what he should do to preserve it and get the most out of it. He needs to know what limitations he faces—for instance, can he drive? Will the automobile have to have automatic transmission; will it be a small car, a large car? What kind of extra benefits can he get by making special efforts to engage in such activities

as skating, skiing, and swimming? He wants to know what new things are coming up which might reduce his level of disability, and how relevant they are for him. Getting factual information was considered important as it gave him the chance to cooperate with those who were providing treatment to achieve a successful result.

Team members sometimes tend to leave the patient in the dark, treating him as an object rather than a person. Standoffishness was greatly resented. Two suspicions were entertained: one, that the treatment staff really didn't know what to do and were not prepared to admit it; and, two, that the treatment staff didn't consider the treatment program something the patient needed to know or should know, perhaps because they wanted to stay in control.

Some treatment staff members indulge in horseplay or flippancy in the belief that this lightens things for the patient. The patients indicated that some lightness was appreciated, but in excessive quantities it was usually not welcome. They wanted their problems to be dealt with seriously. Joking suggested that it wasn't so serious, or perhaps was something they could be jollied out of.

Humorous exchanges between themselves during rehabilitation and friendly competition were helpful. On the other hand, organized mutual support groups were only of interest as pressure groups which would solve social and other problems for the members of the group. Thus, the Amputee Association in Manitoba started out to be a social group and ended up getting prostheses and orthoses covered by medical insurance through a Brief presented to Government. When such a pressure group is formed, they felt it should be headed by an amputee who had had training as a social worker.

When all was considered, those to whom the amputee turns for information may not remain constant. As rehabilitation moves along, he finds new possibilities for obtaining information from different people. At first it is the physician to whom he looks for every sort of support. One amputee referred to his family doctor as "terrific." It was the care given not only to him but to the family at the time, and, through bringing other professionals into the scene at the right time, this doctor gained a lot of credit for himself from the particular amputee. The surgeon is all-powerful in the early stages. The therapists who spend a great deal of time with the amputee are in a strong position to give information. The prosthetist, too, has a strong position in this situation later,



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and, for many amputees, he is the most continuously seen professional to whom they come through the years for replacements, adjustments, repairs and supplies. The social worker usually has a strong place early in the process, or for cases in need of continuous support, but these amputees were not much interested in social workers except to get something needed when the situation was critical, and their own capacities to deal with such a situation were low.

ABOUT THE STUMP.

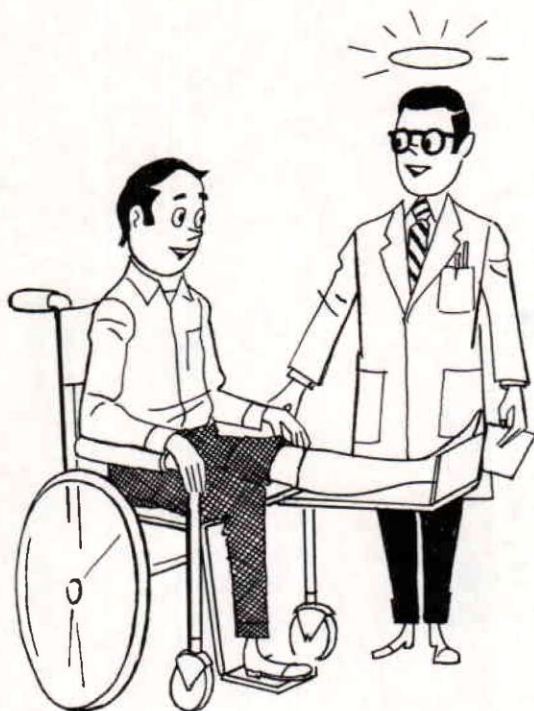
After amputation, the patient generally experiences considerable pain. Amputees want this pain explained. They tend to feel that it is a unique experience with them and that they are being childish about it. Also, they feel the stump to be vulnerable. All mentioned this concern. A common fear is that the stump will burst open if it is stressed when the amputation is new. The doctor can do much to still this fear by demonstration. He can pull up on the end using hand traction on the skin—"That's a good, strong, well-healed end!" The patient needs to be assured that

the pain will gradually diminish, and that wearing a prosthesis will accelerate its reduction.

While the physician may best give information on pain, the prosthetist can reinforce this information by recounting the common experience that use of the prosthesis helps reduce pain. Although awareness of the stump is persistent, awareness of pain and the vulnerability of the stump disappears in time. The amputees questioned mentioned how even a temporary prosthesis was welcomed because of the protection it offered the stump.

AWARENESS OF DISABILITY

Immobilization was a source of great frustration. Later, the encumbrance of crutches was frustrating too, even though walking was possible. When he has a prosthesis, the slower pace he must follow while those around him speed on is a source of frustration to the amputee and brings on feelings of insecurity and inferiority until he comes to a "what the heck" position, and goes his own pace, leaving the normals around to adapt. Among the worries these amputees indi-



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cated they had was that they would not "measure up"; that is, would not be able to achieve their reasonable level of performance.

Acceptance of disability was enhanced by good rehabilitation, and especially by good prosthetics care. Considerate handling also helped. When a patient was made to feel guilty, or to feel that he was a failure, acceptance dropped off. Realistic vocational counseling also helped to improve acceptance of amputation by settling unknowns, or by helping to do so.

Failure at the social, family, or work levels, or in the rehabilitation setting, reduced acceptance. High expectations by those who asked more of the situation than was reasonable were deleterious, unless the amputee could maintain his perspective.

A poor or unc cosmetic prosthesis reinforced feelings of inferiority and inadequacy, while a good prosthesis had the opposite effect. The more nearly normal the prosthesis appeared, the closer to normal their gait, the greater their feeling of adequacy. The desire was to disguise abnormality. A good gait helped accomplish this goal. At the same time, in order to avoid unprofitable effort, the amputees felt that the goals set should be realistic and not require too much

energy. The need for compromise should be indicated when necessary. Realistic struggle was considered to be a positive element in that winning through was a source of satisfaction and increased the patient's acceptance of his disability.

These experienced amputees indicated that frustration and retreat from acceptance of disability did occur. The difficulty in keeping up in social activities requiring increased effort, or in standing for long periods, was mentioned. Their solution was to rest before such activities, and wind down with further rest afterwards. At such times they also took better than average care of their stumps and prostheses to increase their margin of tolerances and safety.

FEELINGS ABOUT THE PROSTHESIS

A good prosthesis becomes something approaching a part of the amputee as time goes on. It protects his stump, returns some function, and gives him a more normal status. He may claim that what it looks like is not important but, in fact, if it is comfortable, he will look for improvements in its appearance. All stressed that they preferred a good-looking prosthesis, including one that was noise-free and dependable. Things they wished for in addition were softness,



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a more normal color, and some adjustability so that they could relieve flare-ups of discomfort by shifting forces.

They all felt that further design improvements were possible, and some were interested in trying new things.

Feelings of anxiety which related to the prosthetist taking the prosthesis away for adjustments were discussed. They feared that it might be spoiled, and wanted information as to what was going to be done, and why. This probably accounts for the frequency with which amputees will follow the prosthetist into the shop if permitted to.

Any malfunction that creates an embarrassment to others is an embarrassment to the amputee. Such things as a foot dropping off are funny enough to recount, but not so funny when they happen. The horror of losing suction was referred to, and some safety method to forestall the occurrence of this catastrophe would be desirable.

REHABILITATION STAFF AND NEEDS

Meeting the prosthetist early, even preoperatively, was reassuring to the amputees. When this preoperative contact was followed by the imme-

diately or early fitting of a prosthesis, the impact was greater. Early provision of a prosthesis cut short brooding and gave the amputees something positive to think about. They considered getting the prosthesis the highest form of psychotherapy. It kept the focus on real things even when there were other challenges to be dealt with.

Seeing other amputees at various stages of rehabilitation was a very positive thing. They needed to understand the differences between themselves and others so that their expectations for themselves were kept realistic. An above-knee amputee cannot be compared to a below-knee or a hip-disarticulation amputee. The subjects felt that the amputee needs to know from the start that work on his part is involved if the best results are to be achieved. For optimal gait, extra effort is required.

Demonstration by another amputee in their category was rated as desirable. He should be straightforward about it, not showing off. They also considered it important that the amputee be shown a temporary prosthesis, and, at the same time, a finished prosthesis so that he would be able to see that one was a "stepping-stone" to the other, and that each had a place in the process of rehabilitation. This exposure to other



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amputees, and to prostheses, should be as soon as possible after surgery.

LOCOMOTION

Therapists tend to explain normal locomotion to amputees, and to urge them toward walking in a normal manner. The subjects felt that such explanations do not convey to an amputee how he should walk. Demonstration by an amputee who has the same category of disability is considered to be the better course. They found that their gaits deviated from normal, and that there was little they could do about it, unless they were willing to tolerate discomfort and increased expenditures of energy. It was their feeling that therapists also tend to move in and take over too readily. The first standing-walking experience on a prosthesis was rated as having the most fantastic impact. It was agreed that at this stage the prosthetist and therapist should be wary so that no setback occurred as a result of unbridled activity. Nevertheless they should be careful not to blight this keenly felt experience. Because sensitivity to pressure is low initially, the amputee can easily overdo it during this first experience.

Treatment staff members tend to see the amputee as his disability relates to their own specialties. There should be an integrated approach to rehabilitation so that the members who

most nearly meet the requirements of the amputee in the psychological sense lead the team. If there is someone outside the team who has a strong position with the disabled person, he should be included. Similarly, in dealing with the home situation, the strongest member in the home should be used in support of the amputee and the rehabilitation effort. For one, his small son was a source of strength; for another, the wife. The clinic team must include the amputee or his spokesman in their deliberations. Dictatorial treatment or rifts within the team were resented. The amputees wanted to be recognized as having a point of view and a strong interest in what went on, and they wanted team members to give evidence of mutual support to one another.

The prosthetist has a very polarized relationship with the amputee. This is because he intervenes between the amputee and pain, and pain is a very strong factor in the acceptance or rejection of a prosthesis. The amputee expects his prosthetist to have the highest degree of knowledge in his field. He wants him to have a polish similar to that of the doctors and therapists and other professionals with whom he deals. Good handling by the prosthetist was highly appreciated, and poor handling deplored in very strong terms: "The prosthetist was poor; turned me off. His manners were poor. He was rough. There was no commu-

nication. I hated him. I accepted what he had to offer, but I was not happy, and did everything I could, including fixing my own leg, to avoid him." Another said: "He really knew his business. He explained everything to me just the way it happened. What a difference it made compared to previous experiences. I knew I could trust him."

Handling the patient doesn't mean pandering to him. The amputees indicated that when the prosthetist is not sure whether a change should be made, he need not feel vulnerable. He need only be definite about the situation. Making fake changes to appease the patient was considered bad because, sooner or later, the prosthetist would be found out and his reputation affected. What the amputees wanted in their prosthetists was competence as indicated by actual results. When amputees raised questions which the prosthetist could not answer, the prosthetist should say so. If it seemed to warrant it, or the patient had strong feelings about it, he should be directed to someone who has the answer, or the answer should be found for him.

For most amputees, the therapist came next to the prosthetist as the most influential person ultimately. This was because of the long periods of time she spent with the patient. She was often his avenue of communications to all the other professionals.

While social workers rated low in these amputee discussions, many social problems were discussed. This probably indicates that the best use of social workers is not realized when amputees are being dealt with, or at least in the areas from which these amputees came. They expected the social worker to know what was available to them in the community—medical services, financial support, written material, organizations, other amputees from whom they could get information, etc. They felt that the social worker could be important to the family, and in bridging the gap for the amputee in the community and at work.

They indicated that amputation is a crisis for everyone involved in the work, and in family and social environments. There is a strong desire to get things sorted out and to close the action. The

hospital was seen as a refuge to which an amputee might cling if things were not going well. In the event of dire stress, his wish was to get back to it. Thus, going home was a highly charged experience often anticipated. However, they needed to come back to the hospital to recoup spent energy, with a mixture of feelings, and give the family a similar "breather."

The forces at work were the reaching out toward more independence within his new status as an amputee, and the need for protection from too much stress. Spouses were strong supporters while the crisis was hot. Later, reaction set in. They became physically and emotionally exhausted. The amputees considered that the social worker, or some other competent persons, needed to be there to support the family under these circumstances. The reactions of friends and colleagues usually depended on the amputee's own acceptance of the situation. Some were squeamish, and couldn't overcome it. Some gave very active support through money collections, looking after the family, and engaging socially with the amputee. These endeavors were highly appreciated. Amputees want to be socially acceptable, and such support is reassuring. On the other hand, all admitted that at times they had used the fact of amputation and the prosthesis as a power lever at every level.

Financial deprivation was discussed. One said that it was a great relief to know that he was covered by insurance. They all felt that prostheses should be part of a medical insurance scheme. They said that such coverage relieved the amputee of concerns about costs, and gave him the feeling that he would be rehabilitated to optimum levels at a time when he had strong financial worries. There were other important needs. Most amputees need a car. Special parking arrangements were needed because of the longer time it took them to walk from one spot to another, and the effect distances had on their total performance. Also, just being an amputee is more expensive because of such factors as getting off work to obtain medical and prosthetics attention, greater wear and tear on clothes, the cost of prostheses and special supplies, etc. Tax relief is considered to be only fair.