

PSYCHOLOGICAL ADJUSTMENT

Benjamin J. Murawski, Ph.D.

There is no sure or easy way to provide a person with information or skills which will allow him to cope with a treatment and a changed life style he has not yet experienced. This is particularly true with kidney disease, since it is not like the usual medical illness which can be treated by a doctor with perhaps only minimal participation by the patient. In the case of an infection, which can be treated by antibiotics, all the patient need do is take the medication as prescribed. Even though taking medicines on a rigidly prescribed schedule should be relatively simple, people do forget to take their pills with them when they leave the house, for example.

The reason kidney disease is different is because it is *chronic* and *progressive*. Except for prescribing dietary restrictions, the doctor is relatively helpless. The doctor has no cure to offer; only at a certain point can he offer dialysis to imperfectly substitute the washing of the blood which the kidneys, when healthy, do so easily and perfectly.

The job of coping with and living with kidney disease is almost totally in the hands of the patient. The role of *doctor-patient* is reversed to *patient-doctor* in the sense that the patient is really in charge of the treatment; he or she must take an active role for it to be successful. The patient has to reorganize his/her life to accommodate the dietary and fluid restriction and the change in daily activities to go to the center for treatment. No longer is the patient totally free to plan his/her life; the medical condition comes first, all other activities have to take second place. This is why kidney disease is different, why it is called a *chronic* condition; it is life-long and requires changes in the patient's life style to accommodate the demands of the treatment. It also means a long and continuing partnership between patient and doctor. This cannot be emphasized enough. The usual doctor-patient contact and contract are different in many ways, and how well things go depends on what the patient does, how *actively* he participates in treatment, how well his family and marriage hold together, and how well he can deal with the stresses of life on an artificial kidney.

Since most patients are treated at a center, this discussion will deal mainly with the tasks of a patient undergoing treatment at a center. The patients on home dialysis have to deal with similar psychological problems, but there are differences.

It will be important to remember that one's feelings and outlook will change as treatment goes on. After the first few dialyses, which will clean the blood of many poisons, you will feel much more yourself, more alert, less fatigued. This has been called by some the "honeymoon" phase. As time goes on, however, the full impact of the many changes you had to make in your life will hit home. You will not necessarily feel progressively better, your spirits may drop, and discouragement and depression may set in. This is quite normal, and the staff, family, or friends will help you if you let them know how you feel; others have been down that road before.

While the tendency is to withdraw from others when depressed, just the opposite needs to be done. If you let people know how you feel, they will try to help. Your doctor may prescribe medications to lift your spirits.

In time, and this will vary from person to person, you must resume work or other activities on a full-time basis. It will mean pushing yourself, extending your efforts even though it seems like your energy is drained. If you know you cannot return to your previous work, you should very early seek job retraining by asking to see a social worker. We have found that those who adjust best to dialysis are those who continue to work; in the case of a homemaker, she resumes her housework on a full-time basis.

FAMILY AND MARRIAGES

It is a rare marriage and family that avoids stress, conflict, anxiety, and unsettlement while a member is making the psychological, emotional, and financial adjustments which are bound to occur while coming to grips with dialysis treatment. Disruption, discomfort, disillusionment are inevitable at some point. Friends rush to help the sick, but they don't intend to stay; neighbors and friends extend themselves in emergencies, but it is the family that is expected to deal with the long haul.

Every effort has to be made to keep the marriage and family intact, since the presence or absence of support provided by family members affects health and recovery from illness. How this works is unknown but it does work. The same is true for religious beliefs. In our experience, practicing one's religion is more important than the type of church one attends.

The tendency, however, is for the patient on dialysis to withdraw from social activities outside the home and rely heavily and exclusively on the family. We do not know why this happens, but it certainly is not necessary and unwise psychologically and emotionally. The larger the number of friends, the greater the diversity, the more likely a solid network of support is available to the patient. For example, if one has maintained contact with friends or relatives in another part of the country where dialysis facilities are available, quite inexpensive vacations can be taken which otherwise might be too expensive or difficult to arrange. With the facilities now available, vacations, that important restoring change of scene and pace, need not be denied to patients undergoing dialysis treatment. With the likelihood of a change in income either because of inability to work or the expense of the treatment, only inexpensive vacations are likely to be possible and only possible if contact is maintained with friends and relatives. The practical aspect is far less important than the support a network of friendships provides. The people around us need not be seen; letters maintain contact, and that important invention the telephone is even better. However the way, keep in touch, do not rely exclusively on the immediate family for support.

One of the stresses dialysis places on the marriage is what we call *role reversal*, which happens if the patient-husband was the primary bread winner and can no longer work at his former occupation. It can be very stressful to accept the change from being the person on whom others depend to become the dependent one. This is a particularly difficult change for patients on home dialysis if the husband has to give up control and depend on his wife's skill in inserting needles and regulating the equipment—in our culture typically male activities. It is difficult enough to be dependent on the machine for one's life; to be dependent on the person who was formerly dependent does not come easily and may be fought

vigorously by the husband if, in fact, or in his eyes, his wife was of the "weaker sex."

SEXUAL ACTIVITY

A very wise physician predicted some time ago when dialysis was first available that the emotional problems of dialysis patients would not be fully appreciated for some time to come. He correctly reasoned that the concern with keeping the patient alive would be uppermost in everyone's mind, and not until the treatment was refined and became routine would anyone have the time to look at patients and ask what was going on inside them and in their lives. He knew that there would be an emotional and psychological cost, and time has proven him right.

It was not until 1973 that a survey was done on a large group of patients to find out what the disease and the treatment does to sexual desire and drive. Man's sexual interest and activity has deep biological roots; how else would man have survived as a species? Yet we all know that sexual urges and expression are highly sensitive to how we feel emotionally and physically, the situation, the receptivity of our partners, the recency of the last sexual activity, etc., etc. A man may be satisfied with twice weekly intercourse with his wife, for example, yet find himself having intercourse twice in an evening with his lover. His hormonal levels have not changed, the intensity of his sexual stimulation has.

Just as we stress the importance of the relationship with the doctor, of equal importance is open communication between the patient on dialysis and his/her loved ones. While dialysis reverses many unpleasant feelings and states it does not necessarily restore sexual energy and may in fact produce less interest and desire. Patients typically report they can "take it or leave it" when asked about sexual desire. We do not know why this happens but fortunately studies are being conducted to search for the cause or causes and if hormones are being washed out in dialysis. There are ways to correct and restore this vital part of life and living.

In the meantime the partner should realize that loss of interest in sexual activity *does not* mean loss of love or that he/she is no longer desirable.

Except in relatively rare cases, the male patient on dialysis can perform the sexual act; he only feels the desire less intensely and therefore performs less frequently. The sexual partner obviously has to make adjustments, but there is no reason why he or she could not provide the setting and stimulation to arouse the partner to a level of excitement for both of them to obtain the needed pleasure and release that sexual activity produces.

What we are saying is that sexual appetite may change in patients on dialysis, and as such, adjustment must be made. It is a problem which can be worked on, however, and needs to be openly discussed and jointly tackled. For some couples, intercourse is the chief form of expressing love and affection; for them alternate ways of filling these needs and finding these pleasures will have to be developed lest each feels undesirable and unloved. These feelings rapidly lead to depression.

Probably the single most difficult psychological adjustment is an internal one and involves using *denial* as a protection against facing the reality of one's illness and its treatment. This is not unique to kidney disease. Some patients in the early stages of a heart attack will attribute the crushing pain of damaged heart muscle to "indigestion." This is an unconscious reaction and protects against the intense anxiety that would accompany realization that death may be imminent. This goes on even though another part of the individual knows that delaying emergency medical attention increases the risk of death.

Denial is part of everyone's method of coping with life. In measured doses it is healthy, when excessive it is dangerous. Ignoring dietary and fluid restrictions is the way excessive use of denial shows itself in patients on dialysis. Without some use of denial who would fly in an airplane or drive a car on a holiday weekend when statisticians can accurately predict the number of automobile deaths that will occur?

Striking the right balance between denial and recognition may not be possible without professional help. A person using denial excessively is most unlikely to recognize this and ask for help. Family members may recognize it, and certainly the doctor and dialysis technicians will recognize it because deniers will not follow instructions. In the extreme case they may miss

treatments because they convince themselves that either they don't need dialysis or feel well, so why bother. Professional help is available and should be used.

One thing is clear with dialysis, in fact any long term disease: support from the family is critical. This includes children. While the sight of blood moving through tubes into a whirling machine may be frightening on first exposure, the unknown is equally frightening. With repeated exposure and information, fear diminishes. Anxiety about dental procedures, for example, is greatly diminished if a child sees dental procedures on specially prepared television tapes before visiting the dentist. This is not true of the unknown; it remains frightening because knowledge or familiarity cannot take place when dealing with an unknown fear. For patients on home dialysis there should be no locked doors, and for children the ideal arrangement would be to have the area in which dialysis occurs also be suitable for children's play. The association of pleasurable activities with a medical procedure quickly crowds out fears and worries. While hooked up to the machine, physical participation with the children in play is not possible, but verbal participation and involvement in children's play is definitely possible. Children are flexible and can adapt surprisingly well if they are aware what has changed in their lives. Dialysis cannot be kept secret, the treatment is just too time consuming, and the access is visible for all to see. As in most disfigurements, others are less shocked than we fear they are or might be.

Family involvement in treatment, whether in center or at home, is not without stress, and weak points will be exposed. Asking for professional help early can prevent serious rupture in the family life. Anything that weakens the support felt by the patient is very likely to affect treatment. Sticking with diet restrictions, for example, is very difficult if we are upset or in an atmosphere of quarreling, or if irritation pervades family life. Not eating enough is as bad as eating the wrong foods. Everyone has to be aware that their lives will be affected some way, and that adjustments will be necessary; some of these are major. Being aware that we will have to make changes allows us to identify the problem and then to cope with it.