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Psychological damage is very common in people with chronic disease and their families. It is therefore important that hemophilia care is extended to the whole family.

Recurrent feelings in families in which one or more members suffer from hemophilia include:

In the patient:

- Worry and fear for own health, exacerbated by parental anxiety
- Feeling different
- Tendency to hide or ignore illness

In the mother:

- Feelings of guilt
- Excessive involvement
- Nervous tension
- Hyperprotecting behaviour

In the father:

- Feelings of isolation
- Psychological escape

In siblings:

- Feelings of abandonment
- Feelings of guilt with regard to their own health

In the absence of appropriate social and psychological supports, the uncertainties and anxieties felt by the entire family will inevitably influence the mental

‘Listening Center’ plan for hemophilic patient and his family

health of the child with hemophilia. It is therefore important that psychological support is offered to the whole family and not just to the child with hemophilia.

The proposed program will offer:

- Guidance and advice in managing the more difficult aspects of hemophilia, and information about the services and opportunities which are available
- Short parental education courses, considering basic developmental psychology and the feelings of the patient and of every member of his family
- Opportunities for parents to discuss their anxieties, needs and expectations with parents of other hemophilic children and with a psychologist

It is necessary to select, for such functions, adequately motivated and prepared staff (psychologists and volunteers). The operator must be careful and sensitive, able to relate to people of different ages, and able to understand the potential fear, pain, illness and uncertainty associated with hemophilia. Staff must have not only sensitivity and empathy, but also a balanced attitude (not indifference), to protect them from an excessive emotional involvement.

The project, for a term of one year, has the final objective to find, in the patients and family, greater serenity and mastery of their own condition.

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