



Huntington's Disease Society of America

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Occupational Therapy In HD Patients

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The day center program is basically group oriented. An Obvious reason for this is that there are more people requiring help than there are helpers. However, there are important reasons for conducting a group program. Individuals derive various benefits from being part of a group. The benefit derived from the group depends on the particular person and the type if group they are participating in.

There are many types of groups, ranging from informal to highly structured and formal. As an occupational therapist, my interest is in running groups structured in such a way that those involved will gain some 'therapeutic' benefit.

As a result of Huntington' Disease. HD patients may suffer from varying degrees of intellectual, psychological and physical problems.

Intellectual

- Planning abilities
- Insight
- Judgment/reasoning
- Memory
- Creative thinking
- Diminished orientation (time, place, person)

Psychological

- Inability to come to terms with their disorder (denial)
- The grieving process – due in part to the distress of knowing you have a terminal disease, and the loss of physical and mental function
- Behavioral problems (attention seeking, abusive behavior)

Physical

- Poor coordination
- Poor balance
- Decrease stamina and endurance
- Dyspraxia – inability to link 'thought' to 'action'

Any group that is run within the program must be structured to best meet the needs of the patients. However, it is not simply a matter of providing a ready-made group for the individuals to attend. One of the most vital factors in any



therapeutic group is the commitment each person has to the group. If the person is not committed in some way, then they are unlikely to derive any benefit from it. Getting that initial commitment is the hardest task of all. That is a topic all on its own. At times it may be necessary to exert some pressure in order to encourage someone to join at least part of the program. Once this first step is taken, it is often easier for that person to become involved in the rest of the program.

One of the major assumptions we make in regard to the day center program is that participation will benefit the individual (physically and mentally, i.e., increased quality of life). If an individual does not find anything of value within this type of program, then this person may be better off in a different sort of institution. This would also open up the group for someone else who might benefit. However, before such a serious step is taken, every effort on the part of both resident and helpers must be made to overcome initial problems.

Our day center program consists mainly of 'activity' groups (e.g., cooking, bingo) and discussion groups (e.g., current affairs). The commitment lies in the activity itself, rather than in any commitment to other group members or to a specific desire for 'self-improvement.' Hopefully, in time, a commitment to the group itself will come from that initial commitment to the activity (i.e., cohesion, support etc. will build up in the group).

There are certain things we aim for with our day center groups so that positive experiences are gained by those participating in them:

1. A high level of input from participants so that they play an active part in deciding what groups are run, and what goes on within the group. This ensures commitment to the group and that the group has meaning for the individual.
2. Activities structured specifically to accommodate the needs of the HD patient (intellectual, psychological and physical, as described above). 'Structure' includes such things as difficulty of task, number of people in groups, nature of task, etc.

I have chosen a few groups and listed some of the factors that are worth considering in thinking about the therapeutic value of the activities.

COOKING

For many women, cooking is something to which they can easily relate. As wives and mothers they have cooked over the years for their families - it is a task they know, and one in which they can actively contribute (bring special recipes, stories of past experiences, as well as actually doing the cooking). However, for other women this very familiarity can be threatening - the fact that they need assistance to cook highlights the deterioration that has occurred as a result of HD. Men can also derive much benefit from this group, but I have found they tend to consider it a "women's group" and prefer not to join.

Participants benefit from this group in a number of ways:

- SENSORY STIMULATION:
Through most of the senses
- PHYSICAL STIMULATION:
A large variety of motor patterns are used in this activity - stirring, cutting, rolling, etc.
- MEMORY AND INTELLECT:
Following recipes, planning what to do next and recalling past cooking experiences.
- ACHIEVEMENT:
In this group, as in others, we try to ensure success. This is a major motivating factor. Achievement and success are directly linked to an individual's self-esteem. Repeated failure invariably results in discouragement and diminished self-esteem.
- FUN:
Cooking usually generates good spirits.
- RESPONSIBILITY:
Choosing recipes, sharing and dividing up tasks, and participating in the task as a whole (from 'measuring up' to 'cleaning up') tend to foster a sense of responsibility.
- FAMILIARITY WITH TASK:
For those who have cooked before, it is a task that does not require much new learning. For those patients with significant intellectual impairment this is important. For them, learning a new task is very difficult and can lead to anxiety, frustration, and a lowered sense of self-esteem.

ARTS AND CRAFTS

For these sorts of tasks, fine manipulative skills, coordination, and fairly acute visual and perceptual skills are needed. For those with most of their physical and mental abilities intact, this can be a very fulfilling and rewarding group. For those with perceptual problems and involuntary movements, it can be very frustrating. However, with appropriate selection and adaptation of tasks, most people can still be involved at some level. The tasks need to be simple enough to match each patient's abilities, but not so simple that the patient finds them 'child-like' and demeaning.

- PHYSICAL:
Use of various manipulative and perceptual skills and fine coordination helps maintain and/or improve these skills.
- CREATIVITY:
Creativity can be expressed through the use of various media, some of which may also provide an outlet for pent-up anger and frustration (e.g., kneading pottery

clay). This form of expression is more acceptable than physical aggression (e.g., kicking someone) and is particularly important when other forms of 'release' are not available, (e.g., when a person is unable to verbally express him/herself, and cannot relieve frustration through a run or a workout).

BINGO

We sometimes tend to be a little derogatory toward this activity, but it does have value.

- o COGNITIVE SKILLS:
Number recognition and numeracy skills.
- o MEMORY:
Long-term - number recognition
Short-term - remembering what number was just called.
- o COORDINATION:
Picking up and placement of tokens.
- o NON-THREATENING:
As it is a game of chance, lack of success does not reflect any personal lack of skill, thus there is no threat to self-esteem.
- o MOTIVATION:
Often patients will join this group when they are reluctant to join others. This could be attributed to the fact that it is non-threatening and/or because there is a prize if you 'win'.
- o CONCENTRATION/ATTENTION SPAN:
This is a learnt ability. The more you have to concentrate, the longer your concentration span becomes. It is surprising how much concentration is required for this game.

WORD GAMES

For some HD patients, physical abilities deteriorate before intellectual functions. It is important for these people to be able to gain a sense of achievement, and word games provide a means by which they can demonstrate their skills.

- o MEMORY:
Obviously long- and short-term memory are utilized extensively in these games.
- o COGNITIVE SKILLS:
Memory and comprehension are involved at quite a high level in this form of activity.
- o ADAPTING THE ACTIVITY:
As the residents are all functioning at different levels, the word games must be selected carefully and structured so that everyone is able to participate.

Structure includes such things as 'cuing in' to the answers, and selection of teams so that there is an even mixture of abilities within them.

CURRENT AFFAIRS

Current affairs is a rather formal name for a fairly informal group. The daily newspaper provides some stimulus for discussion and things go from there.

- o ORIENTATION:
At the start of the group, always go through the date/day/month/year. Going through the day's newspaper articles and reflecting back on previous articles helps recognition of events as being separate in time.
- o MEMORY:
Long-term - relating present events to past events
Short-term - what the news was yesterday, and what today's headlines are.
- o CONVERSATIONAL SKILLS:
Like memory and concentration, conversational skills deteriorate if they are not used. Discussion groups provide an atmosphere which encourages voicing of opinions and sharing of information.
- o SOCIALIZATION:
By manipulating the environment (quiet place, sitting in a circle, and introduction of topics) you encourage individuals to participate in the discussion. Some individuals find it very threatening to 'speak up' in a group setting. Often just sitting in on the discussion and listening is sufficient. More active participation may come later when they feel safe with the other group members, or feel safe with the topic that is being discussed.

I have not covered all of the groups that are currently running, nor discussed any of those proposed for the future, and I have only discussed some of the main features of those I did consider. What I have attempted to do is give some further insight into the value and goals of group work.