

“The Groove ”

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One of the most interesting and consistent findings from the Adult Down Syndrome Center is the discovery that people with DS need sameness, repetition and order in their lives. We call this tendency the “groove” because thoughts and actions of people tend to follow fairly well worn paths, or grooves.

TYPES OF GROOVES

One of the most common grooves is a set pattern or routine in one's day to day activities. Many will often have set methodical and meticulous morning routines for dressing and grooming, daily work routines, as well as evening routines for relaxing and preparing for bed. We have also found that many individuals are meticulous in the care of their rooms and possessions. Much time and effort is spent in making things “just so”. Beds are often made and rooms are neat and tidy. Closets and drawers are quite often in perfect order. In addition, people often have a set place for furniture and other personal items in their rooms or living spaces. Parents and caregivers have found that if any of these items are moved or disturbed by others they will be returned to the original location in short order.

A wide array of other grooves also exists. The most common centers on personal preferences for such things as music, sports teams, or celebrities. Grooves may also include such personal issues as a favorite relative or a love interest. Also common are grooves which have independence issues as a theme. These are often expressed as “I want to do it (a particular activity) by myself and in my own way”. Some people may also develop self-absorbing grooves around emotionally charged experiences. These may involve positive experiences, such as an award, or negative experiences, such as the loss of a loved one.

ADVANTAGES OF GROOVES

There are numerous advantages to grooves. They give an important sense of order and structure to peoples' lives. They also help persons, who process things more slowly in a fast moving world, have some control over their lives. Routines help to organize and manage daily living tasks which increase independence. Once an activity is learned and becomes part of a daily routine, there is rarely a need for “prompting” or supervision from others.

The ability to follow routines at set times each day can be of great benefit. For example, independence is greatly enhanced when a person is able to get up and off to work on his own. Independence and performance may also be enhanced in the work environment. Employers are often impressed with an employee's reliability in completing routine work tasks and in adhering closely to work time schedules.

Grooves may also offer a refuge from the stresses and strains of daily life. This may be especially important to persons with DS because communicating with others may be

tiring and frustrating due to expressive language limitations. In dealing with daily stresses, people will often repeat a specific, enjoyable activity in a quiet or private space. In the worksite, many people will also schedule time during their daily routine, or when needed, to be alone. The most common and often only place for privacy in the work site is the washroom.

Grooves involving the conscientious care of one's appearance, room and personal items can be of great benefit. Such care of one's appearance conveys an image of pride, self-respect and dignity, which will often help develop a good self image. Meticulous care of one's room and possessions may also increase pride and self respect. As an added benefit, family members and caregivers in other settings who share living spaces often appreciate this kind of groove.

Finally, and most importantly, the groove is a powerful means of expression and communication. This is especially true for people with DS, who have limited ability to express themselves verbally. Each groove is a clear and unambiguous statement of a personal choice or preference. For example, daily grooves and routines express how people choose to organize and manage such things as the care of their own grooming, appearance and personal items, their participation in social, recreational, and work activities, as well as personal preferences in music, hobbies and artistic endeavors. Each person's choices will in turn help to shape and define their own unique style and personality.

DISADVANTAGES AND MINOR PROBLEMS

Although there are many benefits and advantages, there are also some disadvantages to grooves that sometimes cause problems. Some of the problems need not be serious if handled appropriately by caregivers. For example a person may be interested in a particular issue, such as a favorite sports team, which they retell over and over to family and friends. While this may be a minor irritant to caregivers, it is not necessarily a problem that interferes with important spheres of living. Additionally there are grooves that may be adaptive if done at the appropriate time or place. For example, a groove for cleaning the bathroom may be greatly appreciated by family members unless it is done in the morning when everyone in the family needs to prepare for work. Similarly, a restaurant manager may be pleased with clean washrooms unless patrons have to wait for long periods while a meticulous job is done.

At the Adult Down Syndrome Center we have also found that a person's need for order or sameness may ironically clash with their need for meticulousness and cleanliness. This is because some people prefer to wear the same shirt or comfortable pair of jeans, over and over, rather than a stiff new pair. Similarly, others may fold and put away dirty clothes rather than have them sit in a rumpled pile in the laundry basket.

MORE SERIOUS PROBLEMS

On the other hand, a groove may become a maladaptive rut when it interferes with functioning in the important spheres of living. There are a number of ways in which this may happen. Some persons may become inflexible about the completion of grooves and routines that may interfere with their participation in other important life activities. For example, one may rigidly adhere to an evening room cleaning and organizing groove rather than choose an opportunity for social or recreational activities which may be beneficial to their health and well being. Some may also make poor decisions, which then become “bad habits”. For instance, we have seen a number of people who have serious problems with sleep deprivation. This may happen if one gets in the habit of staying up late to watch movies or TV, even though he or she must get up early for work or school. Others may acquire unhealthy food habits, such as the intake of too much junk food or soda. Some may get stuck on a particular issue such as a love interest, a favorite celebrity, or the loss of a close relative. Others may get stuck on certain behaviors, which are either part of a regular routine, such as housekeeping tasks, or activities outside one's normal routine, such as flushing toilets or turning lights on and off.

Additionally, the benefits of a groove, derived from sameness, order, and repetition, may become a serious disadvantage in the face of change. For example, gains to one's independence from following a set routine at a set time may be lost if the person is not able to adjust to inevitable changes that occur in daily life. For instance, some may have difficulty changing a morning routine to prepare for an earlier arrival of the bus to school or work. In the workplace people may have trouble adapting to changes in the schedule or in doing activities which are not part of their regular routine.

Apart from daily changes, grooves may also create serious problems for people when they are confronted with major life changes or events, such as transition from school, a move into a residential facility, or the loss of a parent or primary caregiver. These changes often interrupt the bedrock of established grooves and routines which people use to manage their daily lives. In response to these changes some will persist in following old routines or they may get stuck on a particular issue or behavior.

Serious problems may also result if caregivers misinterpret a person's need to complete routines or grooves as oppositional behavior. For example, many persons with Down syndrome try to finish a routine before starting a newly assigned task. Unfortunately, if the careprovider believes the motivation for delaying the new task is to resist authority, then an escalating conflict may ensue. Pressure by the careprovider may cause further entrenchment by the individual with Down syndrome.

A similar problem may occur if the rules in a residential facility interfere with the completion of grooves. For example, in an attempt to be fair, many group home policies specify that residents can only do a particular housekeeping task for one week. As you might expect, some would much prefer to do the same task for extended periods rather than to change every week. Predictably, conflicts occur when the staff tries to enforce this rule. We have encountered these types of problems most often in residential settings

with careproviders who have had little experience with persons with DS. We have also found similar problems in workshop settings. We believe this misinterpretation of the groove is one of the reasons people with DS have a reputation for being “stubborn”.

RECOMMENDATIONS TO CAREGIVERS

When faced with a person seemingly stuck in a groove, we recommend that caregivers first identify and minimize any possible stressors or precipitants to the problem. In some cases, reducing stress may be sufficient to free up someone that is stuck. In other cases action by caregivers may still be necessary after stress is reduced.

When action is needed, caregivers should be careful with how they approach the person who is apparently stuck. Attempts to directly force the person having difficulty with a groove will usually worsen the problem. Caregivers who are most successful at helping in these circumstances, understand the need and benefits of grooves. Instead of a direct and forceful approach, they will slowly and gently help the person resolve the issue in a positive way. This approach will encourage new steps which will become the basis of a new, more productive groove.

Caregivers also need to be mindful that problems with grooves may masquerade as behavior problems. This may occur if a groove is misinterpreted as oppositional behavior. We have found that once caregivers understand and accept the fact that grooves can be helpful, problems are more easily resolved. The tension and hostility derived from misinterpretation of a groove and an ensuing power struggle will often be replaced by a more conciliatory and cooperative interaction between caregiver and the person with DS.

Parents and other careproviders who seek professional help for a person dealing with a stuck groove need to choose a professional who has experience in working with persons with DS. Professionals may be experts about certain things but parents have a lifetime of experience and are experts on their son or daughter. In our experience parents' instincts are usually accurate and they understand the grooves that their family member has developed. This is also true for other caregivers that have had a long relationship with the individual. Be sure that the professional listens carefully and looks at all areas of the person's life (health, significant changes in social, school or work environments or other stressors) for possible causes of the problem. Be sure that the professional does his or her homework before making a diagnosis.

Finally, there are a number of preventive measures which may reduce the chance of problems. One of the best ways to learn to deal flexibly with changes is to have persons with DS begin early in life to gain mastery over small day to day changes and challenges. The earlier and more consistently these opportunities are presented, the more likely people will be able to adapt to life changes when they occur. In this way, individuals develop a comfortable pattern or groove for dealing with change. Another important preventive measure is for parents and other caregivers to attend school or workplace staffings to ensure that others have a clear understanding of the nature and benefits of grooves.