

## **Newsletter Spring 1999**

Editor: Brian Chicoine, MD

### **“The Groove ”**

Dennis McGuire, PhD.

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 ones 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 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.

## **Reaching Out**

Jenny Lobough

The mission of the Adult Down Syndrome Center is to enhance the well-being of adults with Down syndrome by providing comprehensive, community based health care services using a multidisciplinary approach. When the Center was first developed in January 1992, the doctors were able to spend more time getting an eyewitness view of the patients by visiting them at home or in the community. However, the Center is now open five days per week and serves over 750 patients, which makes it very difficult for the doctors to do the community outreach.

In order to expand the services and maintain the quality of care, the Adult Down Syndrome Center Outreach (ADSCO) program was created. This innovative program was made possible by a grant from the Brach Foundation. The goal of ADSCO is to reach out to adults with Down syndrome and promote a healthy lifestyle. Health is more than the absence of disease; it involves a lifestyle that promotes physical, mental, and spiritual well being

and allows social and creative use of one's time. ADSCO enables us to broaden and strengthen the multidisciplinary approach of our community-based center. The Outreach program allows a field member to visit families in the community assessing and meeting needs. We provide support and information to patients, families and caregivers.

The field members include:

Jenny Lobough-Family Advocate  
Certified elementary education specialist with experience in family support and integration of innovative educational interventions in the activities of daily living for clients. Her volunteer services include: advisory board member for Trilogry (a non-profit organization that assists individuals with psychiatric disabilities to integrate into the community) and Minister of Care and participant on Human Concerns Commission of St. Nicholas Parish.

Janice Smith-Registered Nurse  
Community Health Nurse specializing in family outreach and support. She has 22 years of experience in a variety of community health settings. Jan is also a Certified School Nurse, an Assistant Professor of Nursing at Lewis University and a Doctoral candidate at Rush University researching parents perceptions of the spiritual needs of their adult child with disabilities.

Additional members of the Center team who regularly meet with the field staff:  
Brian Chicoine, MD-Medical Director  
Dennis McGuire, PhD-Director of Psychosocial Services  
Karen Cornell-Parent Advocate

Laura Iatropoulos-Certified Medical Assistant

## **My Turn (Our Patients Write)**

Stop the Presses!

Christopher Marsh

Chris M. and Jim T. spent the night of July 24<sup>th</sup> and 25<sup>th</sup> at their “Partners” weekend. Both have been busy this month getting the word out to the village residents about self-advocacy. When interviewed, Chris M. said:

Why we are Self-Advocates;  
When we solve problems, we try talking it out before we get answers.  
When we do find answers and sometimes we get more problems to handle.

Sometimes we get worried when we don't solve them and by the time we get to the solutions we are so tired of solving problems.

By the time we get to the problem, it gets solved right away and thanks to our problem solving had solved the problem.

My Ear Surgery  
Craig Alfred

I do not hear very well and wear hearing aids on both of my ears. Even when I wear them, I still have trouble hearing. Dr. Moore told me about a surgery that could help me hear better. I was afraid that it would hurt. My mom and dad told me it might hurt but if I could hear better it would be good for me. I told them after this “no more surgery”. They said they hoped it would be the last surgery I had, too. My surgery took four hours and I stayed in the hospital one night. I didn't feel too good after the

surgery but I'm glad I had it done because I can hear better. I stayed home from work about a month. My family and the people at the Jewel sent me cards and told me they missed me. I missed work, too. I can hear people talking to me at work better. I can hear everyone better and they don't have to talk so loud. I am glad it's over but I think this was good for me.

Excerpt by Craig's mother:

I took Craig to Dr. Chicoine for a physical when we were thinking of having reconstructive surgery to Craig's left ear. We were told Craig was in good health and decided to go ahead with the surgery after Dr. Moore assured us of the many successes his patients had with it. Craig had a moderate hearing loss in his right ear and a profound hearing loss in the left ear. We hoped it would bring the profound ear up to moderate.

When Craig was about one year old, he started having respiratory infections. They usually ended up as ear infections. Over the years, Craig needed tubes eight times and had become allergic to penicillin and sulfa drugs, which are the drugs of choice for ear infections. It was getting increasingly difficult to treat these ear infections with the allergies to medication and becoming resistant to other antibiotics over the years.

We were fortunate to finally meet Dr. Moore, an ear specialist and surgeon. He suggested we think about having Craig's tonsils out, as they were a source of infection to his ears. We took his advice and had this surgery when Craig was 22 years old. He also told us after the surgery that if these infections stopped for about a year, we should

think about having corrective surgery which included removing scar tissue left by the tubes, repair the perforations in the ear drum and replace the tiny bones worn away by water damage. We decided to have some tests taken of Craig's ear and think about the surgery. We tried to think about Craig's future and decided it was worth a try. We have been very pleased to this point. He has only had a preliminary hearing test and his hearing is noticeably improved. Others outside of the family have noticed Craig is talking so much more. Our dogs barking is the one thing Craig keeps complaining about as I am sure he could not hear it that well before. We can speak to Craig in normal tones and he responds. We were never sure if Craig couldn't hear us or did not understand what was being said or was ignoring us. I'm sure it was a combination of all at times, but we feel confident now that he, at least, is hearing us better. We were naturally afraid to put him through any surgery; this one was well worth the chance.

## **Thank You**

Thank you to all those who were able to donate to the Center in response to our annual appeal. Your generosity helps us continue to serve the needs of many adults with Down syndrome. In 1998, we served approximately 500 different individuals with Down syndrome for a total of approximately 2500 visits to Dr. Chicoine or Dr. McGuire. Thank you for helping make the Center possible.

## **Where, Oh Where?**

Ann Jonaitis, NADS Resource Coordinator, 847-795-2431

The other day I had a phone call asking if we had any books on grieving for someone with Down syndrome. I looked in the NADS Resource Library, confident that we did. Imagine my surprise and disappointment when I discovered that all three books were gone-not checked out-not fallen behind some other books-just disappeared! I had nothing to offer the person.

I then checked to see if any other books were missing and counted over thirty! This is a large number from our small library. What has happened? Where, oh where are the books? Were they picked up to be browsed, then mistakenly taken home? Did someone think they were free? Are the check-out instructions not clear? Whatever the case, we need them back. People are asking for them.

Please, if you see any of our books, return them to us. They all have numbers on the spine and pockets on the inside with our name, address, and phone number. If you can't return them in person, there is always the post office.

I am happy the books are being read, but I do need to keep track of them so others may enjoy and read them, too. Any help you can give me will be greatly appreciated.

## **Opportunity to Participate in A Research Project**

### **Orthopedic problems**

Numerous orthopedic abnormalities are associated with Down syndrome. Common problems such as subluxation and dislocation of the cervical (neck) spine (including atlanto-axial

instability), hip, and patella (knee cap) may cause significant health problems. Generalized ligamentous laxity is the underlying cause of these manifestations. Little has been reported about the natural history of orthopedic disorders associated with Down syndrome in later life. The objective of this study is to determine the prevalence of cervical spine instability, precocious cervical degeneration, degenerative scoliosis, spondylolithesis (slippage of vertebrae), and appendicular abnormalities of the shoulder, hip, and patella in a population of adults with Down syndrome. Approximately 200 adults with Down syndrome (age 18 and older) are being sought for this survey.

### **Why this study is important to the people we see at the Adult Down Syndrome Center?**

We became interested in this question when we started to see several people with instability of the neck that resulted in pressure on the spinal cord that resulted in neurologic impairment. We had previously been recommending that all our patients receive one lateral neck x-ray series in adulthood (once they stopped growing). However, as we started to see more people with neck problems, we knew we needed more information.

### **Who is conducting the study?**

Dr. Steve Mardjetko, an orthopedic surgeon who specializes in spine problems, has seen several of our patients and expressed interest in further evaluating orthopedic problems of persons with Down syndrome as they age. Dr. Mardjetko and the Adult Down

Syndrome Center will be conducting this study.

### **What does the study consist of?**

Individuals will undergo a complete orthopedic, neurologic, and radiographic (x-ray) assessment. The prevalence of orthopedic abnormalities due to generalized ligamentous laxity will be determined.

### **Where will it be done?**

The exams and x-rays will be done at no charge at Dr. Mardjetko's office which is in the Parkside Building, next door to Lutheran General.

### **Institutional Review Board Approval**

The Institutional Review Board of Lutheran General Hospital has approved this study.

### **How do I get further information or sign up**

For further information or to sign up to participate in the study, please contact Leonard Basobas (in Dr. Mardjetko's office) at 847-375-3000, ext. 3071.

### **Sleep Hygiene**

David Duff, MD  
Family Practice Resident at Lutheran General Hospital

As many of you are already aware, women and men with Down syndrome

have a much higher rate of Obstructive Sleep Apnea, a disorder causing decreased quality of rest due to halted breathing while asleep. It can lead to excessive daytime sleepiness, chronic fatigue, and possibly more serious health problems.

While it is important to be aware of this potential sleep problem, something that it often overlooked (by people with and without Down syndrome) are the day-to-day sleeping habits known as “sleep hygiene”. Just as good dental hygiene involves a set of planned activities such as brushing and flossing your teeth, choices and plans you make during the day can affect how healthy your night’s sleep ends up being. It is estimated that about half of all patients who come to doctors’ offices admit, when asked, that they have some type of problem sleeping.

One night without good sleep does not have much affect on our performance the following day. Add together a string of bad nights and you start seeing effects. It is hard or impossible to stay awake during the day (especially for “boring/repetitive” tasks), tempers are shorter, creativity suffers, and you can start feeling “run down” all the time.

Here are some suggestions for ways to improve the quality of normal sleep-to have good sleep hygiene:

- 1) Set a daily bedtime and a wake-up time. Stick to this schedule, even on weekends.
- 2) Exercise daily, but not within an hour of bedtime if possible. Late afternoon may be the best.
- 3) No caffeine after lunchtime. It would be best to avoid it altogether (it stays in your system 12 to 15 hours), but this habit is hard to break. Caffeine includes coffee, black tea, soda pop, and, yes, chocolate. Herbal tea is O.K.
- 4) Minimize sleep interruptions-keep noise/light levels at an absolute minimum (snoring roommates can be a problem); make sure the room is not too hot or cold; don’t drink a lot of water before bedtime; have a comfortable bed.
- 5) No big meals within 1-2 hours of bedtime. A light snack is O.K.
- 6) No smoking---ever.
- 7) Wind down toward the end of the day. No challenging or upsetting activities (if possible) in the evening. This can mean setting aside time earlier in the day for thinking through difficult issues or problems.
- 8) Avoid taking naps during the day, especially in the evening. If you do nap, nothing longer than 20 to 30 minutes.
- 9) Use your bed only for sleeping. No TV, reading, homework, eating, etc.

As with all people, there will be differences between individuals on the amount of sleep needed (6 to 9 hours per night seems to be the average), what activities help or hinder sleep, and just how much chocolate actually counts as a caffeine risk. It is also normal to have sleeping problems when going through difficult or stressful time in life. If the disturbances continue for weeks, however, it is time to get help.

The direct impact of Down syndrome on sleep is not fully known. There are some characteristics that many with DS may find keep them from sleeping as they could. A group home environment or having roommates may lead to more disruptions of sleep. Sorting through emotional, complex, and stressful issues may take more time and effort leading to increased time lying awake “just thinking”. Regular exercise is also lacking for some adults with Down syndrome.

Finally, as every human ages, there are expected changes in sleep habits. Staying asleep is more difficult; older adults wake up more frequently during the night and early morning. The amount of deep sleep is less than in young adults. With these changes comes an increase in daytime sleepiness and napping. Other medical problems can begin to interrupt sleep and the natural body sleep cycles become irregular.

If you suspect someone you know needs help with their sleep hygiene, start keeping track of bedtimes, wake-up times, and the other issues listed above. Try to make some of the sleep hygiene modifications to fit your particular needs.

## **Good night and sleep dreams.**

### **Caregiver Support Group**

A support group for siblings and parents, who have a family member who is facing the challenges of aging and decline, meets on the second Tuesday of every month at 1:30 at the Adult Down Syndrome Center. If you are interested in joining this group, please contact Karen Cornell, the Parent Advocate. Her phone number at the Center is 847-795-2311.

**We ask ourselves, “Who am I to be brilliant, talented, gorgeous, fabulous?”**

**Actually, who are we not to be?**

**You are a child of God, your playing small does not serve the world.**

**There is nothing enlightened about shrinking so others will not feel insecure.**

**We were born to make manifest the glory of God that is within us.**

**It is not just in some of us; it is in every one of us.**

**When we let our light shine, we unconsciously give others permission to do the same.**

**As we are liberated from our deepest fears, so by our presence we liberate others.**

**From the 1994 inauguration speech of Nelson Mandela**

**Our deepest fear is not that we are inadequate.**

**Our deepest fear is that we are powerful beyond measure.**

**It is our light not our darkness that most frightens us.**