Untie the Elderly®

a program to eliminate physical and chemical restraints in health care settings

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A Personal Experience

from Beryl Goldman, Director of Untie the Elderly®

Last month, my 89-year-old dad died. He did not suffer an extended illness but this past year was certainly a difficult one for him and for our family. Until earlier this year, he was in relatively good health and prided himself on taking just one baby aspirin per day. In February, after driving himself to his physician for a regular check-up, he was told he needed a pacemaker. Spending a couple of weeks in the hospital with minimal ambulation set him back quite a bit so he transferred to a rehabilitation facility to improve his ambulation abilities and increase his strength. This was followed by a few weeks of physical therapy at home, but he never completely returned to the same level of function. He experienced a couple of falls when he ambulated without the walker or cane, and occasionally misjudged the sides of the chair when he went to sit—a problem we easily solved by getting a chair with arms.

Til and Bill Sherman

In October, while standing with a group of friends, he apparently lost his balance, fell, and fractured his left hip. Following surgery and a few days in the hospital—during which he was sporadically confused—he was transferred to the same rehabilitation facility that had been so helpful to him earlier in the year. Without adequate discharge information, and not aware of his occasional confusion during his hospital stay, the rehabilitation staff was alerted by my mom that, while in the hospital, Dad had tried to get out of the elevated bed with four bedrails. The rehabilitation staff assessed him and decided it was appropriate to use two quarter rails to assist his movement while in bed and placed a bed alarm on the mattress in case he attempted to egress without notifying the staff. Within 12 hours he attempted to get out of the bed on his own, fell, and suffered extensive bruising on his left side. He was immediately transferred back to the hospital's Critical Care Unit for observation of his injuries and provision of interventions to treat the difficulties encountered in stabilizing his vital signs.

Dad experienced some highs and many lows over the next three weeks. Various combinations of treatments and medications were attempted to treat the systems' failures that were occurring. When I asked if he was receiving pain medication, I was told he never asked for it or he denied pain if they asked him directly. This was a man who never could describe pain but, of course, that's not

Let us hear about your challenges and successes. We invite you to submit an article for publication to **Untie the Elderly**, P. O. Box 100, Kennett Square, PA 19348. Deadline for next issue is April 30, 2003.

Visit our Web site at: www.ute.kendal.org

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something the hospital staff would know. What they should have known is that a person, regardless of their age or mental capacity, with a recent hip fracture, additional injuries, and confined to bed due to his compromised cardiac condition, most likely did have some degree of discomfort. They started him on pain medication and he seemed less anxious and more alert.

Because of frequent choking episodes, a swallowing study was conducted. A feeding tube was inserted which he removed four times during his hospitalization. For some members of the family this was a sign that he didn't want it; for others, it meant he was confused and not capable of making that decision. The staff restrained his arms, something I couldn't bear to see happening to my dad. I offered to stay with him to avoid the restraint use and I was assured they would call me if he became anxious, leading me to believe (maybe I wanted to believe) he wouldn't be restrained. Unfortunately, they never called me and each time the family came to see him, we removed the restraints that were strapped to his wrists.

In an effort to begin normalizing his life, hospital staff began offering thickened liquids and pureed foods. The nurses and speech therapist attributed his poor oral intake to his inability to swallow and his propensity to aspirate...probably not the case, since he just didn't like the food or the "liquids" being offered to him. I was certain of this when, one day, I came into his room and he asked me for water. I needed to respond that he couldn't have it because they were afraid he would choke. We continued to offer him the thickened liquids and pureed foods, but he refused. When my mother told him that he needed to eat to gain his strength, he looked up at us and said, "it's too late." At that point, we were certain what he wanted.

The following morning, after discussion with his physician, we agreed that my dad would have the feeding tube out and he would be transferred to a facility of our choice. I visited my dad more determined than ever to get him whatever he wanted to eat or drink. As soon as he saw me, he asked for water. He thoroughly enjoyed the water, a small sip at a time. He then wanted scrambled eggs and sherbet. The challenge here was that the physician never changed his order and the nurses and dietary staff were not willing to address it with him. After much discussion, the dietary department offered pureed eggs but we emphatically stated that he wanted real eggs—ones that looked like eggs and tasted like eggs. Once he eagerly ate a small amount of the eggs, he asked for his sherbet. This was truly the only time that we ran into an extremely authoritative nurse who, with her hand on her hip, said that even if the doctor ordered the sherbet, she wouldn't give it to him because he would aspirate. I informed her that we would be getting him sherbet either at the hospital or at a store. Not knowing that I was a nurse, she responded, "and when he chokes, do you know how to suction him?" to which I answered, "yes." My husband bought him fruit sorbet which he gleefully, but slowly, ate and, whenever we came back to his room, he asked for more. Never did he have a problem eating it. As my husband entered his hospital room the day before discharge, my dad said to him, "Before you sit down, I want some ginger ale." It's what he wanted and what he enjoyed.

My dad died a couple of days later in the rehabilitation facility, a place that was comfortable and familiar to him. The staff kept his bed in the low position, put one side of his bed against the wall, and placed a floor mat next to the bed when no one was with him. Our family developed a round-the-clock schedule so he was not alone. This was comforting to him, and to us; when he woke suddenly he would see us and immediately settle down. His last few hours were spent with my mom, his children, and grandchildren.

I'm not suggesting that for every situation we should give a patient what they want when it is contraindicated. However, there are times, particularly during the dying process, when a person's wishes and cravings must be granted. We need to allow people to die with dignity, understanding their need to be in control of their final days. Unfortunately, hospitals often are not the best places for people to die because the staff is committed to healing, not to letting go. In the case of my dad, the nurses and doctors in the hospital setting were more focused on saving his body than saving his soul and self respect.

Some tips for family during hospitalization of a loved one:

1 Each hospitalized elder needs an advocate. Listen to the patient—your loved one. Your loved one will feel more comfortable sharing information with you or letting you know what's bothering him. You understand what the person is really saying or trying to communicate much better than the hospital staff. Find out about advanced directives your loved one

has prepared or, if there's not a formal one, ask other family members if the patient offered any information about his desires prior to his illness. Don't be afraid to suggest alternative treatments that may be more in tune with what your loved one desires. It is possible that the health care professionals have not considered it and would be open to discussing it with you and the patient.

2 Fortunately, most hospitals are staffed with knowledgeable doctors and nurses; however, there often aren't enough of them. While agency nurses are used to improve the numbers of available staff, they lack necessary knowledge about the unique needs of individual patients, simply because they don't know them. You do. Give information to the nurses to help them better care for your loved one. Alert them to some of the individual nuances that may improve the overall outcome.

3 Unfortunately, the myth that all older people have dementia still remains in the minds of some health care workers. If your loved one was cognitively intact prior to surgery or hospitalization, and now shows signs of confusion, there is every reason to believe delirium is the cause. Delirium often is underdetected, particularly in the elderly population. Delirium is often misdiagnosed as dementia, thereby resulting in an acceptance of the confusion by the staff or physicians with no attempt to treat the underlying condition causing the confusion. Unfortunately, hospital staff has little knowledge of the patient prior to this experience so family should discuss this issue with the primary physician and hospital staff.

If your loved one does experience periods of confusion or agitation, particularly during the evening or night hours, develop a schedule with family members to alternate times to be with him or, if that's not possible, get someone else who can stay. Let staff know that you will be available to sit in the room or, if that's not permitted, that you will be in the waiting room to assist them whenever necessary. Let them know that restraining your loved one will only increase the agitative state, and will possibly lead to more problematic behavior.

If your loved one is attempting to or actively removing tubes and the tubes are necessary, involve him in alternative distracting activities. Since my dad was a carpet installer, we brought in carpet swatches for him to feel; because of his significant hand strength, we gave him a small squeeze toy for exercise. Also, with his slowly deteriorating ability to extend his arms, we encouraged him to toss a small ball back and forth with me. . .we actually had a great time with this. One consideration that I found most difficult for my family and myself was considering whether my dad actually wanted the feeding tube. At one point we encouraged the doctors to insert a tube directly into his stomach. However, we realized in time that that would not have been his decision so we rescinded our request.

4 Frequently remind staff of who the patient is. Your loved one is not an old, confused person lying in the hospital bed, but rather a person with a history, a person with a family, a person with people who love him. Keep family pictures in the room for all to see. Keep the television turned to his favorite channel or, in my dad's case, to a sports channel. Do all you can to keep the true him alive with the staff.

5 Remember that bed systems (bed frame, mattress, and rails) should be assessed by the professional staff to determine the most appropriate arrangement for your loved one. While bedrails may be acceptable for alert, mobile people, they are often unacceptable for confused, frail elders. I am convinced that my dad would have been at higher risk of more serious injury had he gotten out of bed with the bedrails elevated. Luckily, when he attempted to egress from the bed while in the elevated bed in the hospital, family was there to calm him.

6 Be proactive. Don't depend on hospital discharge planners to find a rehabilitation facility or other long term care facility post-hospitalization. They may suggest one or two places with available beds and, in their desire to discharge the person quickly, will encourage you to transfer your loved one to one these choices. Make sure it's a place that you'd feel comfortable visiting and a place where you believe your loved one will be well-treated. Seek out names of facilities from friends, family, and the ombudsman in your area and take the time to visit and formulate your own opinion. Refer to the Centers for Medicare and Medicaid Services' or the American Association of Homes and Services for the Aging's websites, or your state department of health's website for tips on selecting long term care facilities.

7 Don't be intimidated. As familiar as I am with hospitals, doctors, nurses, and the health care delivery system, I was ill-prepared for the occasional angst I felt when a nurse would tell me that something had to be done a certain way regardless of the wishes of the patient. Speak up and share information that is in the best interest of your loved one.

Untie the Elderly Restructures

After 13 years, the ***Untie the Elderly***® program is restructuring to make more services available to our valued readers and supporters. We remain committed to assisting providers with restraint reduction and delivery of safe, resident-focused care. In our efforts to educate providers, clinicians, advocates, and consumers to the philosophical basis of ***Untie the Elderly***®, and the regulations and quality measures related to the use of physical and chemical restraints, we've expanded our program by developing a comprehensive line of resource materials. In addition, we will make available the materials that so many have found invaluable in their quest to provide better health care for the people they serve, including the *Everyone Wins!* video library, the newly-revised *Untie the Elderly Resource Manual*, and the consumer-based brochure, *A Guide to Bed Safety*, a product of the Hospital Bed Safety Workgroup.

Our restructuring is partially the result of the increasing requests we get for products that could be useful for a person whether in a home, assisted living, acute or skilled care setting to eliminate the use of restraints and to reduce the likelihood of a fall or fall-related injury. Through our years of experience at the Kendal communities, the diverse opportunities we've had visiting facilities across the nation speaking with caregivers and those they serve, we've become increasingly aware of the lack of adequate materials, devices, and furnishings to best meet these needs. While some excellent products are available, the industry lacks adequate equipment to meet the needs of consumers and providers whose goal is quality care in a restraint-free environment.

To that end, we are in the process of developing a catalog of materials that we and others have found favorably acceptable by individuals using them and by those providing the care. In addition, we are searching for a designer to work with us to develop what we believe will be wonderful additions to the options available today.

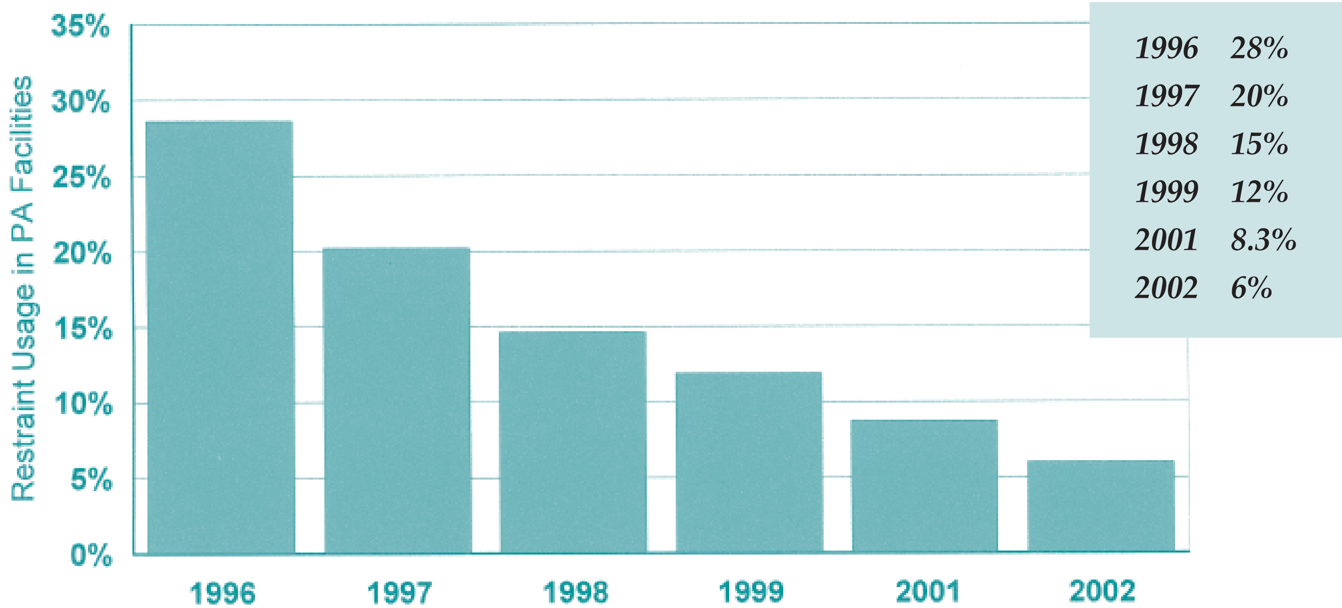
Look for this new catalog in the next few months. As an ***Untie the Elderly***® supporter, you will receive a copy in the mail and, in addition, you will be able to access the catalog on our website at www.ute.kendal.org. We envision this catalog growing according to your needs, so please let us know what those needs are and we will see what we can do to accommodate you.

With printing and postage costs escalating, we'd appreciate hearing from you as to whether you're satisfied with getting the newsletter from our web site or if you wish to continue receiving a hard copy. Notify us by e-mail: mscharf@kcorp.kendal.org or by phone at 610-388-5580.

Joe Tonelli
St. Petersburg Times

Pennsylvania Restraint Reduction Intiative Update

As evidenced by the 23 % drop in restraint use in the Commonwealth, this successful initiative entered its seventh year on July 1, 2002. In addition to providing individualized support to our state's long term care facilities, the four-member training team is currently focusing on fall management and chemical restraint reduction. The successful full-day workshop, *Falls Got You Down? Balancing Resident Autonomy and Safety*, has been received by 472 caregivers and programs will be offered again in early 2003. To date, 77% of the state's facilities have utilized the services of this initiative.



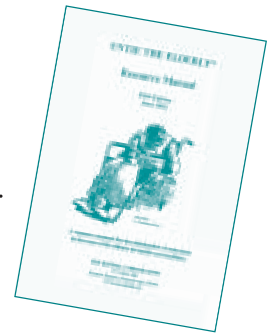
Hospital Bed Safety Workgroup Update

Historically, health care providers routinely raised side rails because they assumed rails provided protection for patients. However, we now know that from January 1, 1996, to January 1, 2002, at least 381 people were injured or died from entrapment in hospital bed systems (bed frame, mattress, and rails).

It is with this knowledge that AARP has recently produced two videos on bed system safety. Both videos explore the long-accepted practice of the automatic use of side rails in all settings, a practice that may not be the appropriate one for each person. The first, a patient/family education video, is designed for use when a person is admitted to an acute or long term care setting, or is in need of a hospital bed at home. The goal is to educate individuals and their families to the myths associated with the use of side rails, and to provide more acceptable solutions for use in different situations. The second, a provider/clinician video, describes the proper approach to evaluating specific needs of each patient so that the most appropriate bed system environment can be developed. This video features some alternative approaches and devices that could be more successful in reducing or eliminating the possibility of entrapment.

Both videos, available only through ***Untie the Elderly***®, The Kendal Corporation, will be ready for distribution early 2003. Ordering information will be posted on our Resource Materials page on our website—www.ute.kendal.org.

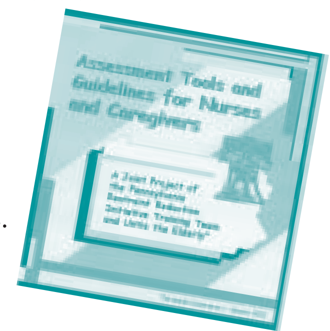
Now Available Two New Tools for Delivery of Safe, Resident-Focused Care



Untie the Elderly Resource Manual, Fifth Edition • $ 120.00

First published in 1989, this effective training manual has just been released in its fifth edition. The comprehensive program, if followed, will assist caregivers in ensuring the older person's basic human right of freedom and autonomy through the elimination of physical restraints. This fifth edition has been expanded to include the following chapters: 1) Adverse Effects, 2) Research, 3) Change Process , 4) Alternatives, 5) Safe Environment (including bed/bedrail safety), 6) Fall Prevention and Management, 7) Assessments, 8) Acute Care, and 9) Legal Issues.

Assessment Tools and Guidelines for Nurses and Caregivers • $ 40.00



Working in Pennsylvania's long-term facilities for six and one-half years now, the Pennsylvania Restraint Reduction Training Team recognized a need for better assessment practices. This resource booklet is a compilation of assessment instruments for Bed/Bedrail Safety, Behavior Management, Environmental Safety, Fall Prevention, General Nursing, Medication Monitoring, Monitoring Devices, Pain Management, Restorative Nursing, Restraint Elimination and Seating to be used in all clinical settings. Most of the assessment instruments have been tested for validity and reliability negating the endless hours being spent on developing interval assessment tools.

To order, see order form on reverse of Resource Material insert.

Untie the Elderly®
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The Kendal Corporation
P.O. Box 100
Kennett Square, PA 19348
(610) 388-5580

Beryl D. Goldman
Director of Untie the Elderly

Lisa Lynch Sweeney
Editor