



The *Gathered View*

National Newsletter of the Prader-Willi Syndrome Association (USA)

The holiday season seems to stress everyone out, despite the joys that it may bring. For parents of children with Prader-Willi syndrome, holiday events and disruptions to family

routines can intensify the year-round stress of trying to avoid excess calories and mood upsets. By New Year's Day, many of us have had it.

To get a good start on the new year, consider some gifts for the caregiver in yourself. In a recent issue of *Exceptional Parent* magazine, Social Worker Brenda Crumpton Sumrall stresses that parents of children with disabilities cannot afford to ignore their own needs: "It's easy to convince ourselves that we must put our children's needs first, but experienced parents often find that they can best provide care for their child when they pay special attention to taking care of themselves. Replenishing your own energy

and well-being allows you to have more to give to your child; failing to replenish it eventually leads to physical and/or mental exhaustion."

Sumrall suggests six areas of "self-care" that can help parents cope with the demands of raising a child with disabilities or special health care needs:

- **Health**—Even small improvements in your own eating and exercise habits can reap big rewards. Remember that daily exercise increases energy and combats depression. (Just 10 minutes a day is enough to start a habit!) Regular meals and adequate sleep boost performance and efficiency. (*See page 3 of this issue for some nutrition tips.*)
- **Support**—"It's important to build a support bank of positive people you can tap into when you're feeling alone." If you have that bank, use it; if you don't yet have the support, find families with similar concerns through PWSA, local advocacy groups, school-based special needs parent groups, or even on the Internet (*see page 5 for Internet resources*).
- **Plans**—Anxiety about the future or about possible problems can be reduced by making plans. This may mean researching services ahead of your need for them (e.g., respite care, schools, residential providers), preparing a will (*see page 4*) or trust, or, in the case of PWS, preparing information packets for everyone in your child's life with a need to know.
- **Goals and Rewards**—Set small goals—ones that you can achieve—and reward yourself when each step is accomplished.
- **Laughter**—"Humor can take away some of the sting of misfortune." Rediscover and foster your sense of humor, Sumrall advises, because "The ability to laugh—and laugh at oneself—is a sign of mental health and growth." She suggests seeking out humorous books, cartoons, and people. (*One of our members shares her wit and wisdom in "The Rat's Tale" on page 7.*)
- **Spirituality**—"Your church or synagogue can be a safe haven and a place for recharging your batteries." It may also be a source of respite care or special programs for your child, Sumrall notes. (*A PW family's book on religious parenting is reviewed on page 6.*)

(Based on "Self-Care for Caregivers," by Brenda Crumpton Sumrall, *Exceptional Parent*, August 1996)

A Gift List for the Care Givers

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The Prader-Willi Syndrome Association (USA)

2510 S. Brentwood Blvd., Suite 220
St. Louis, MO 63144-2326

(800) 926-4797 or (314) 962-7644
8:00 a.m.-4:00 p.m. CDLST

Fax: (314) 962-7869

E-mail: pwsa_usa@aol.com

PWSA (USA) World Wide Web site:
http://www.athenet.net/~pwsa_usa/index.html

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Office Manager - Terry Whitworth

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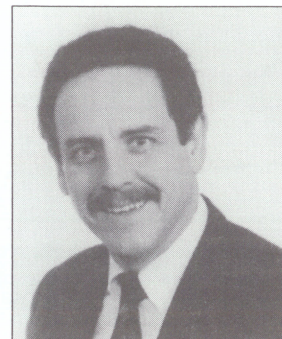
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Out of the Office

by Russ Myler, Executive Director



WHERE IS THE GOOD NEWS?
Where is the positive information
about Prader-Willi syndrome?

We hear these two questions over the phone regularly. Why does the information PWSA (USA) publishes concentrate on the bad stuff? we are asked.

The fact is that the good news is contained within the bad. The information about the syndrome comes from 20 years of parents and professionals working together learning how to save lives. We knew virtually nothing then about managing the many difficulties presented by PWS. Children were dying from any number of causes, but usually from complications of obesity. Many of you remember those days. Now much of that has changed, and people with the syndrome are enjoying better health and a much greater quality of life.

This summer "Scotty" and his parents attended the national conference. Some of you will remember PWSA's "Scotty" brochure, which featured a cover photo of this young man at 299 pounds. Scott has lost the weight and is doing very well. The family erected a sign in the main hallway of the hotel happily announcing "Our Success Story." Theirs, like every family's, was not an easy task, but they succeeded. In fact the success stories are now the rule rather than the exception.

The good news in the information we currently distribute is that if you learn from the information and pay attention to the dangers presented by PWS, your results will lead to many happy times together as a family. There are growing numbers of success stories within the association. These success stories will begin to influence new publications because these success stories will provide new pathways to the management of the syndrome. Walking down these new paths will be the most exciting times of our lives.



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Opinions expressed in *The Gathered View* are those of the authors or editors and do not necessarily reflect the views of the officers and board of directors of PWSA (USA). *The Gathered View* welcomes articles, letters, personal stories and photographs, and news of interest to those concerned with Prader-Willi syndrome.

Editor: Linda Keder, Silver Spring, Md. (e-mail: keder@erols.com)

Associate Editor: Lota Mitchell, M.S.W., Pittsburgh, Pa.

Communications regarding *The Gathered View* or PWSA membership and services should be directed to the national office of PWSA (USA), 2510 S. Brentwood Boulevard, Suite 220, St. Louis, MO 63144-2326. Telephone 1-800-926-4797, or, in the St. Louis area (314) 962-7644. Fax (314) 962-7869. E-mail: pwsa_usa@aol.com.

Diet and Nutrition



Unless you've been living in a cave for the past few years, you know that obesity is on the rise, and that, despite the explosion in exercise equipment sales, most Americans are still couch potatoes. Those of us who have family members with Prader-Willi syndrome probably are more aware than most people of the guidelines for good health, but how many of us actually practice it in our own lives and make it a family affair? You might ponder the following wisdom from various sources, as you review your New Year's resolutions.

What Should We Be Eating?

In response to that question, Bonnie Liebman, M.S., director of nutrition at the Center for Science in the Public Interest (the group that's been telling us the bad news about theater popcorn, restaurant food, and the artificial fat, olestra), offers these tips to "boil down nearly 20 years of research on diet and disease into a simple answer":

- ♥ Avoid ground beef and other fatty meats such as ribs, bacon, and sausage— Use ground turkey breast or "vegieburgers" if you must have burgers.
- ♥ Even lean red meats should be eaten no more than three times a week because of their saturated fat content. (In a later article, Liebman debunks the high-protein diets being espoused in a number of recent popular diet books. *Nutrition Action Healthletter*, July/August 1996)
- ♥ Eat "plants-only" dinners three or more times a week. That means "no meat, seafood, poultry, cheese, or eggs." Add bean dishes (including tofu and other soy bean products) to provide protein.
- ♥ Eat mostly fresh fruits and vegetables (including cooked dried beans, such as chickpeas) for snacks.
- ♥ Use fat-free or low-fat dairy products— i.e., milk, yogurt, cheese, and ice cream.
- ♥ Limit pizza and other "cheese-drenched" foods to only once or twice a month

(unless you make your own and avoid the regular cheeses).

- ♥ Choose whole wheat over other breads, and use whole-grain cereals and crackers. Try other whole-grain products such as brown rice, bulgur wheat, buckwheat (also called kasha), and millet.
- ♥ If you use butter or margarine, buy the "light" tub or spray types. (They are much lower in saturated and/or *trans* fats than the other types.) For cooking, use a spray such as PAM, or opt for olive or canola over other types of oil.
- ♥ Reduce use of prepared foods—Many commercial products are extremely high in sodium. (When you use canned beans, rinse them in cold water first.)
- ♥ Limit sweets, including regular soft drinks. Fat-free baked goods, while better than the regular versions, are loaded with sugars—better to eat whole fruit or other nutrient-rich foods.
- ♥ Keep alcohol use in check—no more than one drink a day for women, two for men.
- ♥ Take a multi-vitamin-and-mineral supplement daily. Men and postmenopausal women should buy one with low or no iron. Women and older people [and those with PWS] also are advised to take calcium supplements.

("a dozen dos & don'ts," by Bonnie Liebman, *Nutrition Action Healthletter*, June 1996, Center for Science in the Public Interest, 1-800-237-4874)

Water—The Miracle Fluid

One bit of advice not included in Liebman's list above is to ensure that your body gets enough fluids to replenish cells and keep systems working properly. In his book, *Your Body's Many Cries for Water*, Dr. F. Batmanghelidj contends that chronic dehydration is the cause of many common ailments. By the time you feel thirst, he says, your body is already dehydrated. Drinks with caffeine, aspartame, or alcohol all have negative effects on the body and should not be counted in the day's fluid intake, he says. Caffeine and alcohol are, in fact, diuretics, which draw fluid out of the body. Plain tap water, chilled to improve taste, is the best choice, according to Batmanghelidj.

While it takes a determined effort to achieve the "minimum" of six to eight 8-ounce glasses a day, just the addition of one glass of water prior to each meal can aid digestion, reduce appetite (in most people), and help start a water-drinking habit. When

you feel thirsty, drink a full glass of water before you reach for anything else.

(*Your Body's Many Cries for Water*, by F. Batmanghelidj, M.D., 1995, Global Health Solutions, Falls Church, Va.)

A Family Food 'Philosophy'

When weight is a problem for any family member, it should be addressed through positive focus on healthful eating for the entire family, according to Dr. Laura Walther Nathanson, author of a recent book on weight control in children.

Dr. Nathanson stresses that parents are the "gatekeepers" for the food that enters a household and that they must establish the guiding philosophy: "Food bought for the family is healthy," and it is prepared in healthful ways that the whole family can enjoy. She advises families to avoid fixing separate "diet" meals, talking about weight and calories at the dinner table, and nagging or teasing an overweight child. There should be a family rule, she says, that mealtimes will be pleasant and that anyone who breaks the rule (including criticizing the food or the cook) will be required to leave the table and forfeit second helpings.

Parents can set the tone, Dr. Nathanson urges, by keeping the focus on health, rather than diet, and by planning table conversations that are "light-hearted and amiable." If a change in diet leads some family members to complain about the loss of high-calorie foods or snacks, this is "not a food problem; this is a parental authority problem," Dr. Nathanson stresses. She offers the following tips for changing the family diet:

- ♥ Go slowly—"Make step-by-step changes in how you shop and cook."
- ♥ Start by changing the content of your recipes rather than your whole meal pattern or preparation methods. (Read those food labels!)
- ♥ Offer dessert less frequently, and don't require that it be "earned."
- ♥ "Involve all the kids in planning, shopping, and serving, but make it fun." She suggests challenging each child over age 7 to help you plan, shop for, and prepare a meal, choosing healthy foods and staying within your budget.
- ♥ "Make sure that there is one dish at each meal that you know is liked."

Finally: "Love every ounce of your kid, and your kid will love every ounce of you."

(*Kidshapes: A Guide to Helping Your Children Control Their Weight*, by Laura Walther Nathanson, M.D., FAAP, 1995, HarperCollins, New York)

WILLS

by William L.E. Dussault
Seattle, Washington

This article is the first of a series on wills and estate planning for families who have a child or children with developmental disabilities. William Dussault, an attorney who specializes in this area, won rave reviews for his presentation at the 1995 PWSA national conference.

Parents are very much concerned about what will happen to their child when both parents are deceased. Parents want to know:

(1) how they can be reasonably certain that after their deaths there will be a friend, advocate, and protector of their child's legal rights available for the child's entire lifetime;

(2) how they can distribute their assets fairly among all of their children in light of the presence of a child with PWS;

(3) how they can be reasonably certain that the assets which they leave for the benefit of their child with PWS will be appropriately expended for the child's entire lifetime and for his or her benefit; and

(4) how they can provide for the financial security of their child without making the child ineligible to receive government financial assistance such as Supplemental Security Income (SSI), Medicaid (medical assistance), and other services, and without exposing the supplemental funds left for the child to claims of the child's creditors and/or the government.

In order to accomplish these goals, parents should prepare a plan for their estate, even if the financial assets that would be included in the estate are minimal. Consultation with an attorney is essential. If you do not have an attorney or if you feel that your attorney is not well-versed in the area of estate planning for a special-needs child, then call your local chapter of The Arc for assistance in locating an attorney who specializes in this area.

Most attorneys who handle wills and estates will be familiar with the estate planning issues relating to federal and state income taxes, federal estate taxes, state inheritance taxes, and federal and/or



state gift taxes but will be less familiar with the special legislation and other considerations which affect persons with special needs. There are many possible tax ramifications that might apply to your particular estate. Such issues must be discussed with a competent professional, and the information must be regularly updated, as state and federal statutes change on a regular basis.

Each Parent Should Have a Will

The basic element of any future plan is a will. A will is nothing more than your own statement of what you want to happen after your death with respect to disposition of your property.

A will is a legal document that should be drafted by an attorney. In your will you specify how your estate or property is to be distributed among various beneficiaries such as your surviving spouse, your children, other relatives, friends, and charitable organizations. As long as you are competent, it can be revoked, amended, or changed at any time during your lifetime, and it does not become effective until your death.

A will can provide for: property distribution; the naming of a guardian, or in some states a conservator or limited guardian; and the creation of a trust, or the transfer of assets upon your death into a trust that has already been created. The execution of a proper estate plan including a will is essential and wise, even though you and your spouse may own all of your assets in joint tenancy with a right of survivorship, community property, or in other forms of mutual property ownership. Even if your assets are very limited and your debts or liabilities may exceed them, a will can still be a useful document for expressing your desires and

intentions on what should happen to your children in the event of your death. Such a personal expression could include the nomination of a testamentary guardian for your minor children or a stand-by or successor guardian for your adult child with mental disabilities.

If There Is No Will

If you die without a valid will, your estate—including all real and personal property owned by you in your name alone—will be distributed to your heirs according to the laws of the state in which you live or in which the real estate is situated. The state will make a plan for distribution of your assets to certain designated heirs if you have no will at all, or if the will you have executed is not valid. The state's plan is known as the law of Intestate Succession and was designed for normal family situations and not for families with members with special needs such as a child with PWS.

If the individual with PWS inherits any of the family's assets in the absence of a will, the court may appoint a guardian or conservator of the estate to administer the property under the probate court's supervision. All investments and major expenditures would then be subject to the advance approval of the probate court. Court costs and delay could result in significant expenses to the estate. When funds are held in a guardianship, the property is considered owned by the ward (the person with mental disability). Accordingly, guardianship property is subject to any claims made by the state for cost of care. Likewise, money subject to a guardianship is considered to be "available" to the ward. If the ward is receiving SSI, Medicaid, or some other governmental financial assistance or benefit, that individual's right to receive the benefits may be terminated until the guardianship property or resources are exhausted or spent down to a very nominal amount.

Thus, in the absence of the parents' own plan, expressed in a carefully drafted will or other carefully planned arrangement, the state's plan is very likely to frustrate the parents' true intent. The guardianship laws, the guardianship court, and the decisions of the court-appointed guardian will control the life of your special needs child without necessar-

ily considering the wishes and desires of you as his/her parent or other surviving family members. Increasing court costs, delays, and the loss of eligibility for needed services and programs may result.

Review Your Wills Regularly

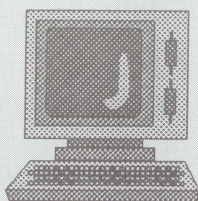
It is recommended that you: (1) review your wills each year to determine whether they continue to reflect your wishes, and (2) at least every five years, have the wills reviewed by a competent professional. Changes in your will may be required by the death of your spouse, changes in your economic condition, the progress of your child with PWS, and other general changes in your family circumstances. Changes in your will may also be required as changes occur in the law relating to taxes, trusts, wills, and governmental benefits and financial assistance.

Should I Leave Money or Property Directly to My Child With PWS?

There is no simple answer to this question. Your estate plan will depend on the size of your estate, the projected needs of you and your spouse, the projected needs of all of your children, the age of your child with PWS, the availability of government benefits, and the laws of the state where you live. In most cases, parents, grandparents, and other relatives should consider *not* making lifetime gifts or bequests via their last wills, etc., to their child or relative who has PWS. Nor should the person with PWS be designated as a beneficiary of any life insurance policy.

Inheriting money or other property including life insurance benefits is, generally speaking, economically "fatal" to the child with PWS for one of more of the following reasons:

- Under the laws of most states, local and state governmental agencies will be able to make charges against the assets owned by the person with PWS or held in that individual's guardianship estate to pay for the cost of care and services provided by the government to that person. In many states, the charges made are developed on a per-capita formula that bears little or no relationship to the cost of services actually received by the individual.



Sites to See

The World Wide Web on the Internet has a vast amount of information and resources that may be of interest to families of people with Prader-Willi syndrome. Finding what you need, however, is not always a simple task. Here we highlight several

Web sites that are helpful, and we'll feature others in future issues of *The Gathered View*. Let us know about your favorites (e-mail the editor at: keder@erols.com).

The Prader-Willi Syndrome Association (USA) site is the place to start. Nearly any search on the term Prader-Willi will bring it to your screen. The latest additions to our site are a bulletin board of inquiries from parents and a trial "chat room" for on-line conversations. (Check the Web site for chat times.) We've also added a page of links to other Prader-Willi sites, including PWSA chapter Web pages. http://www.athenet.net/~pwsa_usa/index.html

The Prader-Willi Foundation site also has information, articles, and parent postings, including a photo gallery. It has links to the Visible Ink Web site, which includes material from *Prader-Willi Perspectives*. <http://www.prader-willi.inter.net>

Family Village is a new Web site created by the Waisman Center at the University of Wisconsin-Madison to organize resources for families of people with disabilities. It's one of the most comprehensive disability sites out there, providing links to numerous other information sources and ways to connect with other parents. On last check, there were several postings by parents of children with PWS. If you're inclined to do your own medical research, there are even links to several sites that provide free Medline searches. (Thanks to Kim Horton, coordinator of the PWS growth hormone research project at the University of Wisconsin, for tipping us off to this site.) <http://www.familyvillage.wisc.edu/>

Michael D. Myers, M.D., Inc., a Web site specifically on obesity/weight control and related issues, provides details on the latest appetite suppressants and other obesity treatments. (Thanks to Dr. Ramasamy Manikam, director of the Kennedy Krieger Institute's obesity clinic in Baltimore, for alerting us to this site.) <http://www.weight.com/homepage.html>

- If a person with PWS directly or through a guardianship owns assets in excess of a very limited amount, that person is disqualified from receiving certain important financial assistance benefits until the assets have been nearly exhausted. If the eligibility criteria for financial assistance benefits cannot be met, eligibility for important corollary service benefits may also be lost.

- Many individuals with PWS are vulnerable to exploitation and are either totally incompetent to handle their own funds or incapable of managing more than their own earnings or nominal amounts of personal property or assets.

- Court supervision of the guardianship of the estates of individuals with PWS may result in more rigid financial management than the parents or relatives desire, and that management may result

in significant delay, court costs, and guardianship fees.

- When a person with PWS dies intestate (without a will) owning money or property, it will be distributed to the next of kin under state law. This may or may not be what that person's parents would have desired to occur for the remaining assets after the death of the individual with PWS. In addition, in some states the state may file a lien for reimbursement of cost of care provided by the state for the individual during the individual's lifetime.

This does not mean that persons with PWS should not be encouraged and educated to learn about money and how to manage it to the degree they are able. It does mean that a carefully drawn will is essential.



Way To Go, Andrea!

In the photo above, Andrea Haller is shown beaming at her successful weight loss—more than 50 pounds after six months on a weight control program that began last December at The Rehabilitation Institute of Pittsburgh. Upon completion of a one-month stay at TRI, Andrea returned home motivated and determined to reach her goal. She was fortunate to receive support and dedicated guidance from the director and staff at the group home where she resides in Presque Isle, Maine.

Andrea is active in a recreation program that provides swimming and daily walking. She volunteers in a Headstart program and assembles Happy Meal cartons at McDonald's, the family business. The daughter of Erich and Pauline Haller, Andrea celebrated her 28th birthday in November.

WANTED

Photos and letters about infants and young children with PWS

Let us share your joys and hopes with others.

Tell us also about your current problems and concerns so we can better address them in *The Gathered View*.

Send letters, photos, or comments to the PWSA (USA) national office.

(See page 2 for address information.)

Book Review

God's Special Child

Lessons From Nathan and Other Children With Special Needs

by Donna and Ellis Adee with Tom Hunsberger

1996, Harvest Publications, 1928 Oxbow Road, Minneapolis, KS 67467
paperback, 147 pages, \$8.95

Reviewed by Linda Keder, editor, *The Gathered View*

In the June 1995 issue of *The Gathered View*, we published Donna Adee's story, "The Special Job for a Special Child," about her son Nathan and his 27 years of living with Prader-Willi syndrome. Nathan's story is now woven throughout an entire book, *God's Special Child, Lessons From Nathan and Other Children With Special Needs*, self-published by Donna and her husband, Ellis, who wrote one of the chapters from a father's viewpoint. Tom Hunsberger is a Maryland special educator and supporter of home schooling who contributed a chapter on learning issues. The lessons from the "other children with special needs" are culled from the responses of some 30 families whom Donna surveyed/interviewed on topics related to raising their children with disabilities. One of the families has a 7-year-old boy with PWS; the other interviews represent a broad range of disabilities. Many of the families are home-schooling their children, and most express strong Christian beliefs.

In the preface, Donna explains that her purpose in writing the book was to "share just a few of the many lessons we learned the hard way," as well as to fill the need for a parent-to-parent book "from a Biblical viewpoint." In fact, Nathan's story and the Bible are the touchstones for this book. Donna has several key messages to offer other parents, and she reinforces them throughout the book with scriptural references and details of her family's experiences with Nathan. With a warm and positive tone, she urges other parents to value their children with disabilities because everyone has a special purpose in life ("God doesn't make junk"), to help their children find their special purpose, to teach them discipline so that they can fulfill that purpose, and to rely on God and their own instincts in making decisions about their child with special needs. The rather academic chapter by Tom Hunsberger, entitled "Learning Disorders vs Character Deficits," draws a distinction between true disability and deficits in discipline or character that require a firmer hand.

Although Nathan was not home-schooled, Donna writes that she would do things differently today. In fact, she expresses a number of regrets about how her family handled Nathan, and she shares these honestly, in hopes of helping someone else avoid her "mistakes." For example:

Nathan, at eight years, started his own style of showing his dislike for the circumstances or rules. He would run away. ... Usually once or twice a month, he would disappear. At first we would frantically look for him, but seldom could we find him. An hour or two later he would come home. He usually walked a mile or two from home. I feel that our lack of consistent Biblical discipline in this area was a bad mistake. We would not have allowed running away by our other children. Why should we expect less from Nathan? The medical professionals told us not to expect much and we thought that they were the experts, but God's Book makes no exception with a handicapped child. Hebrews 12:6-7 ... Every child is different regarding discipline. What works for one child may not work for the other. Once you find what works, be consistent. This is especially necessary for the special-needs child.

This book has obvious appeal for parents who are interested in home schooling and those who share the Adees' belief system. For all of us who have children with PWS, Nathan's story, told in some detail here, will hold interest. Beyond the religious preachings of the book, which may turn off some readers, there is wisdom and support to be found here, especially from experiences of the Adees and the other parents interviewed, about learning to cope and to trust your instincts, teach and discipline your child, nurture yourself and your family, and plan for the future.

SueAnn Walker Belknap, of Corvallis, Oregon, recently began writing stories about life with her son, Casey, who has PWS. She hopes eventually to publish them in book form. The following, one of the first stories she wrote, is published with her permission. SueAnn's story of her family's first PWSA conference experience was published in the April 1996 issue of The Gathered View.

The Rat's Tale

More than once I've been told by well-meaning people that children with disabilities have a special awareness about them to make up for their disabilities.

As much as I love the idea, I wish it wasn't on my mind, because when Casey says something that sounds prophetic I find myself listening acutely. On more than one occasion Casey has stated, "I'm going to die." It isn't a question. He doesn't require an answer. He just says it as a matter of fact. "What does that mean?" I find myself thinking. Does he KNOW something about his own longevity? Will he be here tomorrow? If he isn't, have I loved him enough? Casey says a lot of things so I'm not sure why I worry.

During a Sunday school class Casey was told that when we die Jesus is preparing a feast and we will no longer suffer. Those who are deaf will hear and those who are blind will see. Casey came home and told me, "When I die, Jesus is going to make me dinner and I'm getting new eyeballs."

Death is difficult to talk about. Even so, I was determined to break the cultural norm of silence and talk about it with my children when it was appropriate. With Casey I tend to feel a greater degree of anxiety about when something is appropriate.

I never know how much Casey understands when it comes to real life. Sometimes he will ask me, "Cartoons are pretend, right, mom?" One day he said, "The Flintstones are pretend, right, Mom?" "Uh-huh," I replied. Then he added, "Except Wilma ... she's real." Is a kid who thinks Wilma Flintstone is real ready to talk about death? My plan of action was to present an opportu-

nity by purchasing a pet for Casey and Lindsey with a short lifespan. A creature more substantial than a fish. I chose a pet rat.

A close friend laughed at my choice, saying, "Oh, that would make a great headline ... mother of two on welfare buys a pet rat ... why don't you just use one that's already living in that old house you're renting?" O.K., it was a humorous thought, but I was not going to let it bother me. Our rat "Christine" lived comfortably for her two-and-a-half-year life span before she woke

up wheezing one morning. Her bout with pneumonia before death allowed me to demonstrate the value of life by administering antibiotics and changing Christine's bedding each day with 5-year-old Lindsey glued to my side. Casey was not as interested but watched from a distance.

A few months before Christine became ill, I had remarried. There was so much information in general to share with my new spouse, Lonnie, that I had not taken time to share with him the importance of "the time of the dying rat." I was too busy being involved in the process of the whole thing. Our daily care really dragged that process out.

I was beginning to think that rat would never die. One day after the kids had gone to bed, Lonnie looked at the sick rodent and finally said, "Can't we just throw a little rat poison in there and speed things up a bit?" I looked appalled at my vegetarian, humane-society-supporting, save-the-spotted-owl husband. While trying to hold onto that look, I glimpsed the snow-covered ground outside and thought to myself ... "If I left the cage outside overnight ... " —but I didn't say it out loud. Alas, Christine would have to die a natural death.

Lindsey had been checking the cage daily with a mixture of concern and morbidly eager anticipation. On the day Christine died, Lindsey was not distraught. It was something she expected and was prepared for. Now, I thought, is the time to be careful with my words.

"Can I bury her?" asked Lindsey. "Yes, that would be good," I said. "Can I hold her a minute?" she inquired. I answered, "Yes, it's O.K. to say good-bye to a special

friend." Looking up at me sincerely, Lindsey said, "She was a special friend, that's why I have water in my eyes." I watched my 5-year-old remove the rat's stiffened body from the cage as she observed it curiously.

"I want to show Lonnie," she announced, then skipped back to the bedroom where Lonnie was working on his model railroad.

"Look, Lonnie ... Christine died." From the back of the house I heard Lonnie clearly: "OH YUCK!"

Casey had been sitting in a chair throughout this drama, playing a hand-held computer game. Lonnie emerged from the back room with a "Why are you letting Lindsey hold a dead rat?" look on his face. Without glancing up from his game, Casey asked Lonnie, "Are you going to say 'Oh yuck' when I die?" He stopped playing, looked up at me and said, "Mom, when I die, will you bury me ... I don't want Lonnie to say 'Oh yuck'."

Lindsey's expressive eyes were puzzled. "Lonnie said 'Oh yuck'?" she questioned. I answered her by saying everyone has different feelings about death and maybe Lonnie isn't used to seeing something die—but death is a very natural event. She was satisfied and went outside for the burial rites.

"Will you bury me, Mom?" "Sure, Casey." He went back to his game.

I dug a hole in the yard deep enough to discourage the cats from performing a miraculous resurrection. Lindsey carefully placed the rat in the hole with its stiff little feet pointing straight up in the air and said, "Christine looks like she is sleeping now." Casey joined us for a simple prayer. "Thank you, Christine, for sharing time with us; you were a special friend." Lindsey had been collecting rocks for quite some time. She chose some of her most special rocks to paint with sparkling tempera. Casey and Lindsey decorated the grave with them.

Three years later, when Casey was almost 13, he took a photograph of himself from the bookshelf and put it in my hands. "Look, Mom," he said, bouncing around with his eyes sparkling. "Yes, Casey, that's you." "When I die, Mom, you look at that picture and cry and think good memories of me."

Does Casey not know enough to be afraid of death or does he know more than any of us? Maybe he's just thinking about having dinner hosted by Jesus with Wilma Flintstone as his date. A chance to flaunt a pair of dashing new eyeballs.

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✧ Wishing the New Year's Best to PWSA's Members, Friends, and Angels ✧

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