

THE HALO
AND
YOUR YOUNG CHILD

Practical Tips
for Living with the Halo

A Parent's Perspective



by
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For
Elizabeth
who lived *in* the halo,

Rick,
her daddy and my beloved husband,
and
Sarah, Daniel, Susannah, Anna & Naomi,
her siblings,
who lived *with* the halo

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Dear Parents,

This booklet is forged out of one family's experience with a child in a halo apparatus and in no way constitutes or is intended to serve as medical advice.

When Elizabeth, our four-year-old, was found to have a C1-C2 instability and had to undergo fusion surgery, we tried our best to seek answers to our many questions about the halo prior to its application. We found no resource with answers to the practical aspects of living with the halo. This booklet is a description of our family's methods of coping with the practical demands such a structure makes on your little one and your entire family.

We had approximately two weeks to prepare; you may have had no time of preparation. The things that worked well for us may also work well for you; I hope so. If not, I encourage you to be creative in helping your child cope with the demand this halo places on him or her. Our daughter has a rare form of dwarfism (SEDC) which may make our challenges a bit different from yours, but I suspect you will be coping with similar issues.

As you have probably been told, the halo looks like an awful torture device. I anticipated a horrid experience -- Elizabeth is the kind of child who is in distress if the seam of her sock is out of line, and I truly doubted we'd make it through this. It was quite difficult, but not nearly as bad as I thought it would be, and the difficulties were different than I anticipated. We wouldn't want to do it again, but she did quite well with it and adjusted very quickly. I am very proud of her, as you will be of your child.

I hope the information in this booklet will be a blessing and encouragement to you.

Preparation

Your Child

Unless your child knows someone else who has been in a halo, there is no way you can truly prepare your child for what to expect. Do talk about it, if you have the opportunity to prepare. Tell your child it will feel very strange, very heavy, and will take a while to get used to. Say that he/she probably won't like it at first, but then it will get better. Try not to scare your child, but strive for honesty, too.

Hair

How I wish we had gotten an easy haircut before the halo was put on! Elizabeth had bangs and her hair was below her shoulders. Trimming her bangs with the halo was difficult. A bob-type haircut for a girl would be easy, although it isn't strictly necessary and we did okay without one.

Car Seat

This was a dilemma for us with no perfect solution. We had a 5-point, over-the-shoulder strap car seat which we were able to use, but we had to disassemble it from the back and thread it through the halo, *each time*. This meant a lengthy procedure getting in and getting out, with her in the seat. Add adverse weather to the picture and it was pretty awful.

We finally put her in one of the booster-type seats with the arm across the front and the seat belt over the arm. Due to her short stature, the arm crossed right over the front of the vest and was a smidgen too tight, but it worked. A taller child might find this type of seat perfect if the arm crosses low enough on the torso.

Clothing

See the clothing section. If possible, it would be helpful to have something already altered with you at the hospital for wearing home.

Adjusting in the Hospital

Normal Adjustment

Itching Elizabeth had a great deal of itching after her surgery, lasting about three days. This is normal if your child still needs morphine for pain; itching can be a side effect of the morphine. She had invisible itches inside the vest which were impossible to scratch. We would push our fingers inside the vest for hours -- the sooner you can change the pain medicine, the better. An anti-itching agent can be a big relief. Another aid was one of those small alcohol pads in the hospital -- rubbing one of those on her skin inside the vest (avoiding any sores from scratching) gave good relief.

"Get this off!" Try to imagine how you would feel if it were you in the halo! Every once in a while the inability to cope would seize Elizabeth and she would cry that she just had to move her neck. She also seemed to have painful muscle spasms in her neck. We found that the pain medicine, the anti-itching medicine, and even a tranquilizer was a great help during this short period. Her surgery was on a Monday, and by Thursday she was markedly improved in coping.

Abnormal Adjustment

Itching Our daughter's itching was so intense for a while (she scratched sores on her face and inside the vest), that the doctors started thinking she was allergic to the sheepskin lining of the vest. Find out if your child is allergic to wool before putting the halo on if you can! Synthetic fibers are available.

Fit of the Vest Perhaps due to Elizabeth's dwarfism, she endured a great deal of pain beginning about 24 hours post-surgery. She told us that the vest was too tight, but none of the nurses believed her. When the doctor loosened the vest she gained immediate relief. Have the nurses call the doctor *any time* your child is

exhibiting great difficulty in adjusting. We should have done that earlier.

Remember, you are your child's advocate: nobody else cares as much as you do. Put your little one's welfare ahead of your own reticence to question those caring for your child. See to your child's needs. Defer to the staff's expertise, but tell them what you think is happening with your child. An otherwise superb nurse in the ICU asked us what we did for "time out" discipline because Elizabeth was so distressed -- she thought it was refusal to accept the halo rather than a reaction to the pain caused by the poorly adjusted vest. The nurses and staff will listen to your opinions if you express them respectfully.

Bandage Removal

If your halo experience is similar to ours, you will be removing a bandage at home. She had two incisions from her fusion, one on her hip and one at the nape of her neck. They required no care until it was time to take off the bandages.

This is what worked for us: I took a flashlight, small but sharp scissors, and plenty of patience, care, and time. While she was sleeping deeply, I carefully cut the adhesive of the bandage away from the thousands of tiny hairs that had grown onto the back of the bandage. This took about an hour and a half, and Elizabeth was very restless because it was painful. It would have been a nightmare if she had been awake.

Sleeping in the Hospital

Our hospital provided beds for parents to sleep on in our childrens' rooms. However, the halo prevented Elizabeth from turning or being able to find me if I was on the bed. I chose to sleep in a chair where she could immediately orient on me with her eyes when she awoke. She was disoriented every time, and seeing me gave her security. Is there any other choice?

Clothing

Alterations

We were told that most people just wear big tee-shirts -- that didn't work for us. It was winter, and cold. If a shirt was cut to fit over the halo, it slipped off her shoulders. A talented friend, Mrs. Linda Wooten, made alterations in sweat shirts for her, and they worked beautifully.

Elizabeth is 31" tall, and the halo and vest were 31" in circumference. She normally wears a 2T-3T, so we bought size 4T sweat shirts. I think a size five would have worked even better, as the fit across the back still wasn't roomy enough to cover the vest.

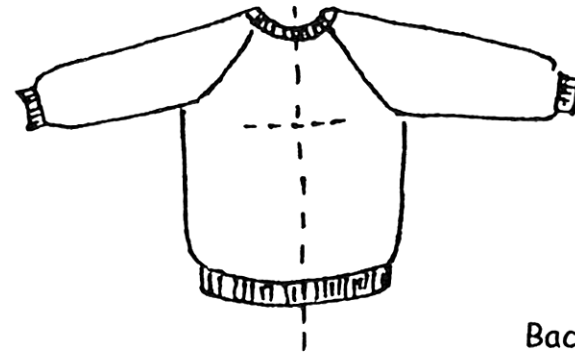
Cuts were made in the sweat shirts (see diagrams), then the cut edges were hemmed to prevent fraying. We used ribbons to tie the cuts together, along with some Velcro in strategic places. Four pairs of sweat pants and five sweat shirts made an attractive, useful wardrobe for the 11 weeks she was in the halo. Spring and summer would require lightweight material, but the basic pattern should work well for any child. Linda applied some lovely work to the sweat shirts which made the clothing attractive as well.

We couldn't get a coat to fit her, so we just wrapped blankets around her in the wheelchair when we were out.

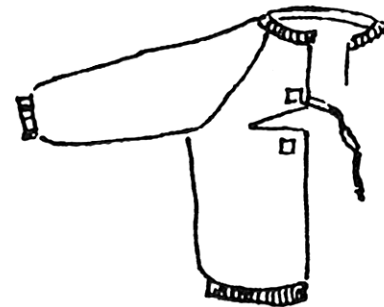
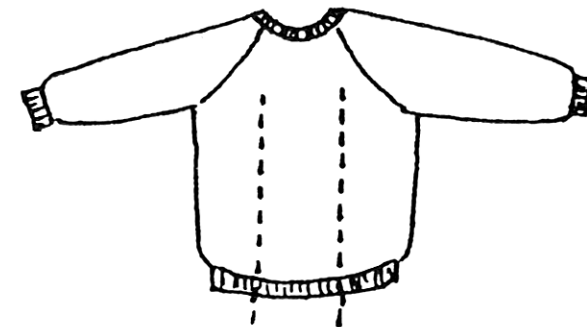
Timing

It would have been wonderful to have the altered clothing available when we left the hospital -- it took us three weeks before she had any clothing to wear. While it will be easier to measure your child after the halo is on, it will make your life easier if you can have at least two outfits prior to getting the halo.

Front



Back



Step 1 - Cut Along Dotted Lines

Step 2 - Hem Raw Edges (not shown)

Step 3 - Apply Velcro and Ribbons

Step 4 - Decorate

Practical Tips for Halo Care

(This is not intended as medical advice. Follow your physician's instructions.)

The Cleaning of the Pins

Importance As your physician will explain to you, it is important to keep the pin sites clean due to risk of infection. Follow your physician's advice on frequency, method, and materials.

Trauma & Tenderness We were told that the pin sites would probably be numb, but Elizabeth's sites were tender the whole period she was in the halo. Your experience may be different. One site was painful the whole time and stayed irritated, and another site became infected toward the end of her stint in the halo. As much as she tried to cooperate at pin cleaning time, it was traumatic and painful.

Pin Cleaning Tips

We developed some coping strategies which were of great help. These two things turned the tide for us.

1. *While Asleep* At first, our instructions were to clean her pins once/day. This was pretty awful for her. We discovered that doing it about 45 minutes to an hour after she had fallen asleep worked beautifully. She would moan a bit, move around, and flutter her hands -- all of which indicated that those sites were truly tender -- but I could get them well cleaned without upsetting her.

2. *Water Play* When the frequency of pin cleanings increased, it was no longer enough just to do it while she slept. Using water as a distraction worked every time, the whole eleven weeks!

I would sit her on the side of the kitchen sink and let her feet dangle into the soapy water. She played and "gave her feet a bath" the whole time. I would clean the pin sites, and while she would say, "Ow, owl", etc., she

didn't cry or fret even once. I rotated toys to play with, little animals, utensils, and the like and it solved that whole situation for us. She was even happy to have her pins cleaned up to four times/day with the water play. Of course, it took a bit longer, but it was worth every second because it changed a dreaded procedure into a warm, fun, even cheerfully anticipated event.

Bathing and Hair Washing

Bathing Since the vest goes down to the waist and cannot get wet, I would bathe her at the kitchen sink as I cleaned her pins. I would wash her bottom half and wipe her arms, hands, and face at the sink. Occasionally, I took a damp cloth and wiped her skin under the vest as far in as I could reach. Since a young child doesn't sweat as an older one does, under-the-vest cleanliness wasn't a problem.

We discovered that things such as a turkey baster and other utensils made this a fun time for her. We also included tooth brushing at this time -- and we let her do most of it, since it gave her a little control over something in her life.

Hair Washing For the first couple of times, we used a "no water" shampoo given to us at the hospital. That was sufficient for a while, but not long. It appears to be important to keep the hair clean since it surrounds the pin sites.

We incorporated hair washing every couple of days with her bath and pin cleaning. I would lay her down on the kitchen counter (on a towel) with her head suspended over the sink basin. The halo was a support to her and as long as she could feel my hands on her, she felt secure. I used the sink sprayer with a mild shampoo.

Living with the Halo

Your Child's Personality

Frustration Whether your child is an easygoing, compliant child or an active, strong-willed youngster, please realize that the halo is producing some level of frustration at every moment and this will affect all your child's emotions. Our experience was not intolerable, but we did have frequent temper tantrums and other venting of frustration (screaming, crying, irritability). Be understanding.

Just think how it feels -- whatever independence has been achieved, from toileting to mobility, has been greatly diminished. You know your child best, but please allow your little one the freedom to express his/her valid frustration at this difficult confinement. You will have to find the balance between allowing that expression versus encouraging him/her to cope. This was not greatly difficult for us, she did very well at adjusting. Your mature, unselfish, unconditional love will be a key factor in your child's successful acceptance of the halo.

It is important to help your child discuss what he or she is feeling -- ask leading questions if you need to. Don't overdo this, but ask if she/he feels sad, angry, etc., and then help deal with those emotions in a positive way. Your reassurance and acceptance will give your child the strength to cope.

Activity & Fatigue When we came home from the hospital, we sat her up in a "pillow house". This meant having several pillows behind her for support and on both sides because if she leaned over to one side she could not get upright again. She would sit upright, become fatigued, and have to recline against the pillows at her back. Six weeks after our return home, she was standing on her own, and eventually was walking independently.

Some of her decreased mobility may be due to her small size as part of her dwarfism, and your child may reach independent mobility sooner. Elizabeth weighed 25 lbs., and the halo weighed 6 lbs -- 25% of her body weight. It takes development of new muscle groups to move with the halo, so expect your child to be more fatigued than usual with an increased need for sleep. She also had a greatly increased appetite, desiring many small meals each day. I would suggest letting your child have as much healthy food as he or she desires, since the increase is probably due to the stress the halo puts on the body.

Entertainment

Head Position Your child will not be able to bend his or her neck to look down to read a book, or to color, or play, etc. This doesn't mean these activities are ruled out, but if you can prepare for them you'll be in a better position than we were.

The *most* useful accessory we had was a small plastic laptop table we purchased at a dollar store. Get a raised table! This lap table with short legs raised her food, coloring books, and other activities to a manageable level. We also used the folding TV trays. Some kind of raised table is essential.

Another useful item was a tabletop easel -- we put it on her table and it raised the papers so she could color, paint, and draw with chalk. It was stressful for her to bend over all the time; the easel provided a welcome change of position. One other helpful tool was a kind of tilted "reader" which was slanted to hold books.

We also had a wheelchair for her, and our computer desk was wheelchair height. This was entertaining for her at different times.

Play Our family has not been in the habit of watching much television, but we relaxed that for her sake. She watched a good many cartoons and videos. It is better for your child to alternate that with some type of physical activity than just to sit and watch TV the whole time.

As she gradually became more mobile, she spent a lot of time playing on the floor with her favorite toys (little ponies). We encouraged her older siblings to give time just to her to help her pass the day creatively.

Eating

The most important thing we found was to raise the height of her food to make it manageable for her. The closer you can raise the food to eye level the easier it will be. When we eat, we bend our necks slightly to see our plates. Your child will be unable to accomplish this. He/she will have to bend from the waist, lean forward, or move his/her eyes to see the food. Try the raised tables, TV trays, etc.

Kitchen towels and bibs became necessities. We just tucked a towel around the arms of the halo to prevent food from getting down into the vest. She was great at helping us remember the towel when we explained how uncomfortable it would be to have crumbs in the vest.

Restaurants We were able to eat out more frequently when she was feeling better and we had clothes for her. A high chair or booster seat put her at the correct level, and we always brought our towels. Go ahead -- go out to eat! The change of scenery will be beneficial.

What about the other diners? The next section deals more with that issue; it wasn't a problem for us. Sure, people stare -- mostly out of kindness, curiosity, or compassion. For her emotional comfort, we always tried to seat her with her back facing the main flow of dining traffic so she would be less aware of the stares she received. A number of people came and spoke with us; we met a lot of nice people this way.

Mobility

The longer she wore the halo, the more mobile she became. Toward the end, she began falling more often, bumping her head and making the pin sites bleed. This may have been because of overconfidence, or just overreaching her abilities. Seek your physician's advice if your child appears to be too active.

Lying Down

Elizabeth was very frightened of lying down on her back. This was probably due to the feeling of her head "floating in space", even though it was stable. An adult friend told us that a soft pillow under the back of the neck helps diminish this strange sensation and makes the head feel secure.

Sleeping

The first night home from the hospital we put a mattress right by the head of my bed and she remained there the whole time. She would wake up disoriented during the night, or be uncomfortable and unable to turn over, or stuck, or need to change position. She also found our waterbed very comfortable. Your child will need to be confident that you are easily accessible during the night if he/she needs you.

Toilet Care

Since Elizabeth was unable to walk for seven to eight weeks, we had to carry her to the toilet, put her on, hold her steady, clean her up and help her off. Her short stature may have contributed to this and your child may be more independent. Personal hygiene may be challenging due to the difficulty in bending over with the halo. Plan to be very helpful for the whole time.

Please take special care not to indicate in any form (sighs, moans, facial expressions) that caring for his/her needs is bothersome to you. It certainly was inconvenient, but your child's self-worth is more important than your temporary trouble. We all took special care to answer with a cheery tone of voice, and I tried to remember to be thankful for the child *and* the halo when dealing with its many inconveniences seemed overwhelming.

Your Child's Independence

As mentioned earlier, much of your child's independence has been compromised or lost. This is one of the roots of the frustration he/she will experience. Every movement will be a conscious or subconscious reminder of that loss of control. The more ways you find to give your child some independence, some control, some *choice* in his/her life, the less frustrating it will be.

For example, we let Elizabeth take over brushing her teeth, whereas I had done that before to ensure effective cleaning. In answering the public's questions, we gave her the choice of answering for herself (she never wanted to), or having us speak up for her. Be creative in giving your child some areas to control and it will make your walk through this experience easier for everyone.

Furniture

Ah, the furniture! After taking my older children to task for scratching our coffee table and hearing their protestations of innocence, the light in my brain came on! After Elizabeth could stand up, she loved to walk around our coffee table and play with her ponies on its surface. The halo was the source of the scratches and gouges! We chalked up the damage to part of the cost of having her whole and healthy, and got rid of it later.

However, one day at church I noticed that the back of the pew was all scratched. Yes, the halo again. After that, she either sat in her wheelchair during the services or sat on a quilt or blanket draped over the pew (her choice of seating). Also, beware your wood floors.

Again, it's important not to make your child feel as if the material things are more important than he/she is. When we visited someone, we would say, "Oh, that old halo will scratch these floors. Let's put this blanket over it." Try very hard not to make your little one self-conscious or guilty about the halo.

Household Temperature

It was winter, and Elizabeth was on the floor most of the time due to her immobility. She was difficult to clothe warmly; we had to keep the heat on more often and at a higher thermostat setting than usual. We just counted it part of the cost!

Other People

Your child will catch your attitude no matter what other people portray. Let me reiterate: Your attitude outweighs any other. Give your child the gift of a positive outlook coupled with acknowledging the difficulties involved.

Other people will generally take their lead from you, too. We found a great outpouring of love and compassion, and even asked several people not to pour on the "bless her heart", "poor little thing" comments since we didn't want her to feel pity as a majority response.

It *is* important to let your child express the difficult things and validate the truth of the experience. You should bathe your child in kindness and compassion, yet also surround him or her with messages which communicate the ideas of:

- (1) "You're doing great!";
- (2) "It's hard, but you CAN do it! You are a strong girl/boy!"

When these messages are internalized, you are gifting your child with the ability to cope and helping to strengthen him/her from the inside out.

Siblings

Depending on the ages of brothers and sisters, you will have to prepare them several ways. For the first sight of their sibling in the halo, prepare them not to overreact, or to show any disgust, fear, or upset. It's contagious! Have them focus on your child's eyes instead of the apparatus. Some of Elizabeth's siblings and cousins found it nauseating at first, and we let them leave the hospital room quietly. Your child needs the acceptance, the comfort, the *normality* of his/her brothers and sisters.

We also taught her other siblings (except the 7-week old sister) to sacrifice for Elizabeth. It wasn't easy, but it was a good opportunity to build character and perform a service. They did a great job and were key elements in Elizabeth's successful adjustment to the halo.

At the same time, realize this halo will impact their lives. It's harder to go anywhere as a family, and harder for you to concentrate on the other children. Make some time for them while your child is sleeping. If your child in the halo has a younger sibling, be sure to give that child all the attention you can. It's an opportunity for all of you to learn to live with each other in an understanding way, and can richly bond you together as a family unit if you so choose.

Halo Removal

Anesthesia or Not?

You should follow your physician's advice. Remember this is just one family's experience.

Our daughter started worrying about the method of removal two weeks after the halo was put on and by removal time had decided she never wanted it off. Given her fear of the procedure and the advice of her pediatrician and others who knew her, we chose anesthesia since our surgeon gave us the choice.

It was still frightening for her to go through the same procedures as she did for her surgery, yet worth having her asleep for the trauma and frightening experience of the removal procedure. We are happy with our decision.

There are always risks with anesthesia, so if your child is less fearful or older, it would perhaps be better without the anesthesia. I would suggest wise counsel from others who know your child and know the procedure.

Neck Brace

Elizabeth received a soft neck brace after the removal of the halo. It took more adjustment than I expected from the information provided to us.

Perhaps due to her short stature, the soft collar did not fit properly and she was in pain from the stretched position of her neck after she awoke from the anesthesia. When the doctor came back, he cut the collar down and she was fairly comfortable afterwards. Be sure to tell the nurses and doctor if your child is more than a little uncomfortable.

Her neck muscles caused less soreness than we expected. We never even had to give her anything for the pain we had been told to expect.

Chafing The collar did cause some chafing on her chin and at the back of her neck where the clasp was. We purchased moleskin and applied it on the collar in those places. Moleskin is a very soft felt found in the foot care section of pharmacies and drug stores. There were no problems after that. It was also easy to change the moleskin for cleanliness; we were less successful in preventing food spills on the collar than on the halo.

Hair Pulling The corners of the moleskin and tape pulled her hair until we got that under control by cutting off the sharp corners and folding under the exposed adhesive which was catching her hair. Take care when removing the collar that your child's hair is not caught in it.

Hair Washing Until we had permission for her to be upright without the brace, she lay down as we removed the collar and I washed her hair as well as her body at the kitchen sink.

Cautions

After your doctor says your child's injury is healing well and you can start weaning him/her off the soft collar, ask specifically how active your child can be and how vigilant you need to be. Can you go to the playground? Can older children carry your child? We did not understand the fragility of the healing process at this point in her recovery; be sure you understand what level of activity your physician recommends.

Yourself

Your Adjustment

There is no way to fully prepare yourself for the sight of your child in the halo. It really looks horrendous. It *will* become tolerable. One of the things I missed most was the ability to hold Elizabeth, to hug her, to feel that little head on my shoulder. I missed being able to give her comfort in that physical way. Bear in mind that it will get better as time passes, and if possible, try to develop an attitude of thankfulness for the halo and the protection it is giving your child.

You may have had this thrust upon you as an emergency situation, or, like me, had a bit of time to prepare. Try to find some time alone to adjust -- to cry, to read, to pray -- and try to find someone to talk to. You'll be more capable if you can vent your negative emotions. Your concern is, of course, for your child, but your child's successful adjustment depends largely on you.

Try to decrease the burden of your schedule for this whole period since the halo makes it more difficult to get around. We were in the middle of soccer season for her older siblings, and I missed a lot of games and depended on others for transportation. Everyone understood that. Your friends will want to be a help to you. Take them up on their offers!

My relationship with God through Jesus Christ sustained me through this period. He gave me strength through my prayers and the prayers of others. I would encourage you to seek spiritual support through this time of challenge.

Others

As mentioned earlier, other people will generally take their lead from your attitude. It would be wise to seek positive support, rather than those people who drag you back down into pity and the inability to cope.

Questioning Your Doctor

Do not hesitate to ask your doctor all of your questions -- write them down to organize them. Be sure you understand the answers in your terms. That communication will improve your understanding and your relationship with the physician through this time. Do not be afraid to call your physician's office to ask questions that arise -- any reasonably competent provider will understand this is new to you and will expect you to have questions.

Closing

From the heart of one parent to another: I hope these things we learned from our experience with a halo brace will make yours a bit easier. We were hungry for this kind of information. No doubt you will develop your own coping tips with the halo; perhaps you can share your discoveries with your provider.

We are storing the halo and pins in a box for Elizabeth when she is grown -- I believe this time of challenge has given her depth and inner strength, and is part of the shaping of the woman she will be some day. We'll give them to her as a visible reminder of how her character was molded as she matured. Help your child turn this experience to the positive. Love him or her through it. There's nothing more important anyone could say.

The Halo's Dichotomy

*Ring of black fire, embracing
Cold metal band, enlacing
Eight pointed teeth pierce to the bone
Resolute armor, confining
Steel bar jungle, aligning
Small, sad face enfolded, alone.*

*Strong shell of protecting
Fortress guardian, caressing
The fragile, new union of bone
Ring of blessing, enfolding
A young soul, enmolding
A fire-forged strength all her own.*