



WHAT AN AUNT CAN DO

by Deirdre Lord

When we first got word of Hayden, and then Cameron's Tay-Sachs diagnosis, we were all devastated. Just like all of you, I wondered how we would get through? How would we get up every morning and go through the day knowing of Hayden and Cameron's prognosis? Then, I wondered, what can I do? What use is an aunt?

Initially, I found that spending time with Hayden, Tim and Alison, and Blyth, Charlie, Taylor and Cameron was the best help I could offer. Hayden and I would sit together. I'd read him a book, give him a bottle. Alison's parents and I spent one Spring weekend with Hayden. We took turns cuddling with him. We all went out for a walk to enjoy the Spring flowers and to hear the children playing in the playground.

I tried to spend time alone with Cameron and Hayden too. These visits allowed me to get some quality time with the children. I learned their pace, their language, and their rhythm. As frequently as possible, I hoped to give Hayden something delightful—chocolate, a tape of music, a good rubdown. I knew he was content, because he would say "NNnnngggg". I loved spending the night with Cameron. I would drift off to sleep to the rhythm of her breathing. When she woke, I would wake up too. We'd talk together in the quiet night. On these visits with Hayden or Cameron, their parents could spend some time together out of the house, or they could get a full night's sleep. It seemed to help. I also had Taylor, Cameron's older sister, over to spend the night. Taylor enjoyed the undivided attention, while her parents had the opportunity to spend time at home with Cameron.

You don't have to live nearby to offer support. At the suggestion of another Tay-Sachs parent, we tape recorded the extended family reading stories to

Hayden and Cameron so that the children could hear us read even when we weren't around for a visit.

Also, don't forget to keep track of how the extended family is doing—talk, listen and learn about the stages of the disease, and how parents and grandparents are coping. Like parents and grandparents, aunts and uncles need to take care of themselves: eat well, sleep, exercise and do things for yourselves. It is the only way to be of any use to the family.

If the child's parents are willing, make sure to help mark important milestones in the child's life—6 months, 1 year, 18 months. It will help to recognize these children as the stars that they are—and will help to celebrate the gifts that they bring us.

As the disease progresses, aunts and uncles can help as caregivers. You will know the child's rhythm, you will know what makes him or her comfortable and happy. When it became difficult for Cameron to eat, I would try to sing lullabies to her as I gave her the bottle. It helped me to relax, and I think it helped make mealtime easier for her too. Near the end of his life, our families took turns spending the night with Hayden. It was quite magical. New York City was quiet! We'd remark on that. We'd read stories or poems when he was awake; tell him how we'd learned about love and life from him; or just sit quietly

and hold his hand.

What good is an aunt after all? The best I could do was what any aunt would do for any child—give love, and bask in the glow that came back from the children. And learn—I learned as much about living during their 2 short years as I had in 33 of my own. These things that I've learned—about love, living life richly and fully, taking care of each day—are gifts that I share with Hayden and Cameron's parents, and all of our extended families. The stories that we tell, the memories that we share now help to remind us of their gifts, and of their presence in our lives.

Inspired by Galway Kinnell
by Alison Lord

The friendly-faced old poet
writes of cold blackberries
and olive branch fires.
He writes of that moment
I think of as ours, in
which your tiny body nestles
between us, so frail.
One week (or more) since you
ate or drank. And still, you
lived, lived to hear the voices
of those who love you still.
To feel their warm embraces.
Finally, quiet. The candle
burns, your sister, sated,
sleeps beside me. And I rest
my hand on your leg, the other
across your golden head to touch
your father. We wait
and bathe in your warmth.
Finally, those breaths
come, and go. And a sigh.
The softest sigh.
And you are gone.