Family Perspective: Why Children's Needs to Grow

When Alexis Douglas was 11 weeks old, she was diagnosed with stage 4 neuroblastoma — a form of childhood cancer — and a 10% chance of survival.

After eight surgeries, 22 rounds of chemotherapy, 12 cycles of radiation and countless follow-up appointments, she is 5 years old and her cancer is considered stable. Though the Douglas family is grateful for the excellent care their daughter continues to receive at Seattle Children's, sharing a hospital room adds to a difficult situation.

Must we share a room?

Jill Douglas, Alexis' mom, says sharing hospital rooms with other patients is one of the most emotionally exhausting aspects of cancer care today. She's thrilled that the cancer unit in Children's new facility will feature single-occupancy rooms.

"Kids are in pain, and they're sick from chemotherapy," says Jill. "When one child calms down, the other child starts screaming. Parents are under tremendous stress. Sharing space under these circumstances isn't fair to kids or their families."

continued on page 2

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> "I never dreamed we would be in this situation. How would you feel if your child or a child you love had to live in a 4 x 12 hospital space for a week? During the holidays?"
>
> — Jill Douglas, parent

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Fear of infection

Infection risk is another worry among families sharing rooms in the cancer unit. A visitor's cough, for example, can easily spread germs to fragile patients. "Kids die of cancer, but they also die from infection," notes Jill. "Children deserve single-patient rooms for their protection."

Waiting for a bed

At times, no inpatient bed was available in the cancer unit so Alexis would have her treatment in a procedure room instead. "To make room for us, the staff would put us in a procedure room with a chair that reclined while we waited for a bed to open up," Jill recalls.

A new standard for cancer care

Children's new cancer unit, scheduled to open in spring 2013, addresses the concerns of parents like Jill with single-patient rooms, increased capacity and amenities that better support families.

Features of the new cancer unit

Families helped Children's design spaces that promote healing and support parents

No more sharing rooms: Capacity will increase to 48 beds in single-patient rooms by 2013.

Meeting developmental needs: Adolescents and young adults will benefit from a dedicated floor of 16 beds.

Privacy and comfort: Patient rooms offer private bathrooms and room for two caregivers to stay overnight. They also include flexible spaces for dining, entertainment and medical consultations.

Maintaining the rhythms of daily life: Quiet rooms for reflection and lounges with computers offer supportive spaces for parents away from their child's room. Lounges also feature microwave ovens, space for food storage and preparation, and areas for families to share meals and conversation.

> "When you share a room, you have to walk past other families' pain."
>
> — Jill Douglas, parent