



## Danielle : an Inner Light Revealed

*by Paule Anges Roy*

Danielle came to L'Arche in 1996 and lived in one of our homes for more than ten years. Before that, she lived with her family who loved her dearly, helping her grow and accept her reality as a person with Down's syndrome.

With us, she was a “live wire”, a beam of sunshine: bubbly, energetic, funny and so people-oriented. Little by little, however, she had to face the loss of control that was occurring in her body and her mind. Her motor skills were gradually affected, and I am convinced she had a certain awareness of this, but nevertheless she remained full of trust and courage.

Eventually we had to adapt our care; we suggested to Danielle and her family that she live in our home for young people with multiple disabilities, a place better equipped to meet the physical needs of someone with her condition. She was able to stay there a year, happy and surrounded with affection. Her health, however, continued to decline to a point where she needed professional care and competence, something we were no longer able to provide.

It is a heart-breaking dilemma that so many must face regarding their aging relatives and those with disabilities. It would be so good to keep them with us! Danielle's family experienced this along with us; it was painful for everyone because we had all been certain we'd be able to keep her until the end of her life. This “certainty” had always been present in our language and desire to welcome at L'Arche.

I am deeply grateful to Danielle's family; despite all the pain and disappointment, they

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remain close and continue to walk with us. Danielle now lives in a nursing home, not far from our L'Arche homes, making our visits easier.

Since I had lived with her and – having retired – am now more available, I was asked to become the contact between Danielle and the community. A real privilege for me! Danielle is now confined to her bed or a wheelchair, incapable of the smallest independent movement – except when she looks at us with her beautiful blue eyes!

As often as possible I try to help her at mealtime and simply spend time at her side, giving her a little extra comfort. We've introduced a communication notebook as a constant link with her family and as a way of sharing everyone's opinion concerning the evolution of her condition.

We have good relations with the nursing home; once a month our Day Program is invited to animate a musical session. It's a good opportunity to get together and express our affection.

A schedule has been drawn up to ensure that our homes visit Danielle on a monthly basis, and we encourage new assistants to get to know her so that her membership will not become "artificial."

As well, we make sure that Danielle's picture is present at our celebrations and community gatherings so we'll not forget that she is still one of us.

In the past I had the privilege of "looking back" with Danielle at "her story" and putting together an attractive souvenir album, and I continue to add significant moments; for example, just recently, her 50<sup>th</sup> birthday!

Throughout her life Danielle has always showed a spiritual interest; we therefore continue to offer her "nourishment" by helping her as often as possible attend Mass at the nursing home.

Personally, just before leaving, I like to be at her side and slowly recite the L'Arche Prayer. At the first signs of her illness, we were able to be present, along with her family, when she

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received the Sacrament of the Anointing of the Sick. A very touching moment – solemn and peaceful.

I can also see how much the nursing home staff is attached to Danielle, her family and all of us. The fact that the mother of one of our assistants and the mother of a former member with a disability (now deceased) are both patients on the same ward creates a certain family atmosphere.

Here is a simple demonstration of how the mission of L'Arche is not limited to living in the homes but that it shapes “another way of seeing” the gift of people who are “different.”

After having experienced dynamic moments with Danielle, exchanges full of life in the midst of the daily routine, I realize how my relationship with her is now at another level – well beyond language that uses only very simple words referring to memories, songs she likes, expressions she used that made us laugh and communicate, gestures of affection that she herself would make towards us, thoughtful acts that brought comfort, etc.....

In fact, all that is engraved in the heart's memory!

What Danielle brought us in terms of joy, surprise and trust lives on with us—in a way transfigured, because her weakness now allows us to see her as tenderness in its “purest form”.

I believe this is perhaps the most beautiful thing L'Arche has revealed to me!

*L'ARCHE L'ÉTOILE  
Quebec City  
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