



## Roger Neilson House / La maison Roger Neilson

October 11, 2016

Dear Roger Neilson House Families,

Over the summer we conducted a review of our support services with a view to identifying strengths and weaknesses in these programs. The families of Roger Neilson House were asked to provide their input and many responded, answering the survey or speaking to us by telephone or in person. Approximately 20% of those contacted responded to our request and we thank you for your valuable input.

We also polled other pediatric hospices in Canada to get a better understanding of the services our colleagues across the country provide to their families. In this respect Roger Neilson House fared well and there were no obvious weaknesses in what is a strong range of services for the entire family (parents, siblings and grandparents) for both ongoing support programs and for bereavement programs. We are very proud of the breadth and depth of the support services offered at RNH.

Today we had the opportunity to share the next steps with our day time support group parents and we will be present at both Family Advisory Council and the evening parent support group in November to listen to any feedback you have on our next steps. As always your feedback is very important to us and we welcome your comments and thoughts.

A part of this review was to ask ourselves if we have the internal capacity, the right people in place to ensure that the services we provide are sustainable. With two full time social workers and a second permanent recreation therapist (our new recreation therapist starts later this month) we feel we are in a good position to move forward with new and expanded programs.

A new support and education Grandparent group will begin later this fall. We will also prepare on line resources for families that request information for far away grandparents.

We also feel there may be value in having a monthly open “coffee chat time” at Roger Neilson House for any families that wish to attend. Families have expressed to us that they feel connected and safe at the house. This group would not be facilitated by the staff but would be a time for parents to connect with each other. It will take place during the day when staff is present to provide support afterwards if needed. We will review coffee chat time in a year to see how this has worked for families.

Not surprisingly, our families were split on whether the palliative care parent support group should be held during the day or during the evening. Holding the group during the day helps those families with school age children attend, while the evening program benefits working parents. We will try alternating the time of the meeting, so that the group meets during the day one month and during the

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evening the next month. Families are welcome to come to both the day time and the evening group. Parents should be aware that should they need individual counselling they may continue to call their social worker as needed. It was also suggested that the palliative care parent support group be renamed and we are open to suggestions. Maddie Arnone will be sending along the dates for the sessions tomorrow.

We are also looking at the possibility of offering childcare during group time so parents can attend. We are looking at the logistics of how this will be offered and how we can organize this. We will be back in touch in November on this topic once our new recreation therapist has settled into her new role.

Once again we wish to thank all those who participated in the review. And please continue to send us your comments and feedback. It is because of your honest feedback over the last couple of years that we have been able to add new programs and tweak existing ones to suit the needs of the majority of families. We will continue to monitor the effectiveness of all of our services and programs to ensure they are meeting the needs of our families.

Sincerely,

Megan Wright  
Executive Director

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Manager

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