In partnership with CHEO

Working Together: Transitioning to Adult Care

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BACKGROUND

Roger Neilson House (RNH) is a pediatric palliative care hospice in Ottawa, Ontario. We work in collaboration with the Children's Hospital of Eastern Ontario (CHEO). Services provided by RNH include end-of-life care, symptom management, respite, emergency respite, perinatal hospice, and transition to home support. RNH also offers bereavement services, memory making, and legacy-building activities.

RNH has an engaged Family Advisory Committee (FAC). This committee identified that there was potential for growth in supporting guests transitioning into adult care. Given this awareness, our team has been striving to develop a holistic process and tools which will facilitate consistency, collaboration, and inclusion of guests who have the potential to transition.

"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully but also to live until you die." - Cicely Saunders

APPROACH

Getting Started

- With the feedback from our Family Advisory Committee, in 2022 RNH began developing methods and tools that would support our guests as they transitioned into adult care.
- During this process we also thought it was important to understand how other facilities were supporting transition to adult care.

Benchmarking

- RNH gained a better understanding that our colleagues from the Children's Hospital of Eastern Ontario (CHEO) and an affiliated treatment centre, Children's Treatment Centre (CTC), were using different processes for transitioning youth. It is not uncommon for our facilities to share mutual patients.

Collaboration

- As discussions continued, CHEO, CTC, and RNH decided to work together to enhance the quality and consistency of the process. We decided to use the same tools, resources, and documentation.

INFORMATION SHARING

We are hosting an information session on January 25, 2024, for eligible youth (aged 14+) and their families. This session will highlight the community resources available to the transitioning youth.

Using a holistic approach, we have confirmed speakers who help coordinate community services and funding, offer respite, accounting advice, and legal assistance. A palliative care social worker will also present to provide awareness of the emotional and psychosocial aspects of transitioning into adult care. Patients and families from CHEO and CTC will be invited to attend which will support inclusivity and knowledge sharing.

CONSISTENCY AND COMMUNICATION

In February 2022, the province of Ontario published the *Complex Care for Kids Ontario Youth Transition to Adult Care Toolkit* which details steps and actions that should be completed to facilitate a successful transition. Our collaborative group felt it was important to utilize that resource to guide our practice.

Fortunately, CHEO, CTC, and RNH all share a common documentation platform. We are currently constructing a "Transition to Adult Care" flowsheet that can be used by our teams and viewed by anyone with chart privileges. This documentation will be designed around the guidelines provided in the provincial resource. If well utilized, our teams will be able to determine what aspects of transition have been covered for the youth and which elements are remaining.

QUALITY ASSURANCE

The RNH team meets yearly with the transitioning youth and their families. During this meeting, we review the provincial document to ensure the suggested milestones are in progress or complete.

RNH Quality Committee decided it was important to monitor the support we are providing to youth transitioning into adult care under our Excellence & Leadership in Care Performance Indicator. Our set goal is to "provide supportive transition to adult care." To measure this goal, we do chart audits quarterly to ensure documentation about transition discussions has been completed. Our target is to have 100% of eligible youth (aged 14+) have documentation and therefore support related to transitioning into adult care.

SIGNIFICANCE

As a pediatric palliative care hospice, we are presented with challenges in the transition phase. At times it is hard to determine if the youth is likely to succeed into the adult years. This can lead into difficult discussions with the guest and their families. In Ottawa, there is not a comparable service to what we offer for our guests in the adult care system.

Navigating the unknown can be overwhelming for families. By working collaboratively and utilizing the multidisciplinary team, we will continue building the youth's legacy and empower families to seek resources and services to feel well situated and organized prior to graduation from our programs.