

New Supportive Community for Pediatric Caregivers

Parents and guardians demonstrate tremendous resolve when caring for their child. For those parenting a child diagnosed with cancer, this courage and determination is amplified.

To help them navigate what can be an isolating and challenging time, the Pediatric Psychosocial Oncology Program at Dana-Farber/Boston Children's Cancer and Blood Disorders Center established a new platform for support called, Parents Together.

Co-created and overseen by clinical social workers Larissa Hewitt, MSW, LICSW, and Kelsey Hamstead, MSW, LCSW, Parents Together aims to create a space that offers a toolbox of educational and supportive resources, and allows parents and caregivers the opportunity to connect with those who are going through similar challenges.

"Part of patient support is taking care of the caregivers," says Hamstead. "Many parents and caregivers of pediatric patients are looking for a network of individuals who understand exactly what they're going through."

Recently, Parents Together established a partnership with Momcology® – a nonprofit support organization that provides national programs and services for primary caregivers of children diagnosed with cancer. Through the use of educational material, as well as private social media groups and in-person events, Momcology helps parents support one another, find timely information, and begin the long-term healing process after a childhood cancer diagnosis.

"Parenting a child after a cancer diagnosis can be an extraordinarily lonely experience," says Hewitt. "Caregivers are faced with decisions and fears that most of their family and friends can't fathom. They often lose connection with those who would usually be a source of emotional support, resulting in isolation. Our programs and resources are designed to help replace that isolation with community," explains Cat Paciente, Momcology director of operations and mom to 14-year-old brain cancer survivor, Luca. "Momcology provides opportunities to meet, learn from, and foster connections with other caregivers who truly understand the challenges of facing a childhood cancer diagnosis."

The new collaborative relationship also introduced a new program called, Connections: Pediatric Cancer Caregiver Support, which is available through Momcology to the Dana-Farber/Boston Children's community. This group is open to parents and caregivers at any stage in the cancer journey, including those who are bereaved. This combination allows for different experiences and perspectives, which participants often find helpful.

"There is a strong need to connect with others who can comprehend what you're going through and offer support," explains Lindsay Maxwell, a parent of a pediatric cancer patient who finished treatment in 2019, and one of Dana-Farber/Boston Children's two Momcology representatives. "It's a chance to understand what treatment and post treatment could look like, and even give some parents hope after their world has been turned upside down."

The Connections group series launched in January and consists of bimonthly virtual events open to caregivers of current and former Dana-Farber/Boston Children's patients.

Dana-Farber/Boston Children's is the first to offer a completely virtual version of what's historically been an in-person gathering. For the 90-minute sessions, participants join via Zoom – and while each event has a specific theme and lesson plan, the needs and interests of the participants dictate the discussions.

"Launching a program intended to provide the opportunity for families to connect and form bonds during a pandemic that prevented in-person attendance had its challenges," Paciente reflects. "Both Momcology and the dedicated team at Dana-Farber/Boston-Children's felt strongly that families needed this intervention more than ever so we made some adjustments and moved forward with the launch in January. It was a decision that made sense to the entire team and based on the response it was clearly the right call. We are thrilled for families at Dana-Farber/Boston-Children's to have access to this psychosocial care intervention."

"Caregivers need this type of program and service now more than ever. By holding these gatherings over Zoom we're eliminating geographic barriers and opening it up to more people."

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“Our first meeting surpassed all expectations,” adds Nicole Abair, co-chair of the Pediatric Patient and Family Advisory Council (PPFAC), and a Dana-Farber/Boston Children’s Momcology representative. “Having the opportunity to be part of this process was incredibly gratifying.”

Looking Forward

Building on this initial success, Hamstead and Hewitt are working to expand Parents Together’s reach and engagement.

Ultimately, their goal is to create and facilitate a supportive community – one that’s aim is to offer parents opportunities to both learn and build connections.

“It has been an absolute pleasure working with everyone and watching this collaboration come to fruition,” says Paciente.

Hamstead agrees. “There are so many ways to offer support, and I’m excited for future collaborations that will allows us to connect and reach more families,” she says. [AF](#)