



The Top Five Reasons Why You Should Refer Your Patients with Life-Limiting Illnesses to Montgomery Hospice

In my primary care practice, I take care of more than 15,000 children in Montgomery County Maryland. Fortunately, the vast majority of these children are healthy and suffer from routine medical issues associated with childhood.

Yet, a small number of my patients have life-limiting illnesses such as cancer, neurodegenerative disorders, and genetic anomalies. Even though I work part time for Montgomery Kids, Montgomery Hospice's pediatric hospice program, I struggle with the decision to refer the hospice appropriate patients in my practice. There are lots of reasons why I hesitate: I feel ill-prepared to have a difficult conversation about end-of-life; I worry that I don't have time to have such a conversation; I don't know how to determine if someone is going to die in the next three months; I fear that the family will think that I am giving up; I hope that the oncologist/neurologist/geneticist is going to make this referral; and, I have to deal with my own reluctance to accept that this child, for whom I care so deeply, is going to die.

I get it. Making a hospice referral for a child is really hard.

So, instead of trying to identify a child you think might die in the next three months, you should think about all of the children who are unlikely to survive into adulthood, and about those who have a high likelihood of dying in the next two years. These are the children who are hospice appropriate; these are the children you should refer to Montgomery Kids now.

Why?

Here are the top five reasons why you should refer these children now.

A child's illness not only affects the child, but also the entire family.

You are not referring just the child to hospice, you are referring the family to a multidisciplinary support group who specializes in managing all of the aspects of life-limiting illnesses that you may not have experience with. The Montgomery Kids team will support the family members while they continue to seek life-saving

therapies, and we will help them manage their expectations and disappointments. We will have the difficult conversations for you. We will guide the families to have age-appropriate conversations with the ill child as well as his or her siblings. We will assist the family in managing their day-to-day affairs while they care for a chronically ill child. We will hope for the best and plan for the worst. We will help them celebrate milestones. We will continue to support the family for two years after the child passes.

NB is a 17 year old with a life-limiting genetic disorder. She has four siblings who are ages 13-24 years old. This young lady had been deteriorating gradually over a ten year period of time when suddenly an infection landed her in the PICU. The previously happy, playful, albeit developmentally-delayed, girl was now bedridden requiring around-the-clock nursing for respiratory support and pain management. The parents both worked full time; two older sisters were in college and deciding if they should take a semester off to stay home with their sister. The younger siblings were scared of how their sister looked and were afraid to be in the room with her. Through much counseling and support, we helped the family secure a hospital bed and nursing support, apply for FMLA, and get the younger siblings to climb in bed with their sister and watch TV.

We are experts in symptom management.

You are an expert in your field. You have practiced and honed your skills at diagnosing the cause of symptoms, determining the best diagnostic tests, and orchestrating treatment plans. Your expertise has helped identify an illness in this child and has improved this child's survival. You will continue to provide this service for this child. At Montgomery Kids, we are experts in collaborating with you and managing your patient's symptoms. We specialize in pain assessment and management. We work with you and the family to achieve as many days as possible where the child feels good enough to go about the tasks of childhood: to go to school, engage in a vacation, and play with friends. Hopefully in your practice, you will never have so many patients who need this type of symptom management that you would have to become an expert. It is our job to be the experts in this area.

JS was a 20-month-old baby with a neurodegenerative disorder. She was fussy and irritable all the time, and could not get comfortable. She was most miserable when she was being held by her parents. She did

not respond to the classic interventions such as muscle relaxers, pain medicines, seizure medicines, etc. Our hospice physician prescribed oral ketamine, a medicine typically used in anesthesia and rarely used outside the hospital setting. Within hours, she was comfortable and awake. Her parents were able to hold her for the first time in months.

We understand pain.

When a child's body is failing, he or she may have many different kinds of pain: visceral pain, neuropathic pain, bone pain, spiritual pain, constipation pain, existential pain, and fatigue pain. We diagnose and treat all those pains, and we address all the pains of the entire family. Our team consists of medical doctors, nurses, social workers, chaplains, and trained volunteers; together we bring a whole host of special skills and interests to share with the child and family.

SS was a four-year-old boy who had no way to communicate if he was in pain. He was completely paralyzed and non-communicative. He had a continuous pulse ox that he wore to monitor his oxygenation and his heart rate. His parents' hopes and dreams would crest and fall with this monitor. When the Montgomery Kids chaplain went to his home and played the harp, his heart rate would go down and his oxygenation improve. We also learned that massaging his hands and feet offered the same result so we arranged for that to be done several times a week. We found that aromatherapy also worked. We will never know if SS was in pain and how much the measures that we took made him feel better, but his parents believed that we made him more comfortable and that allowed them relief from their spiritual pain.

We don't help children die. We help them live.

Hospice is not just for the last days of life when the patient is transitioning. Yes, we are absolutely there for this part of the journey. But the children and families who benefit the most are the ones who have the opportunity to have symptom control early, so that they can enjoy each one of their remaining days. When you refer patients to Montgomery Kids, you are not giving up on them. You are telling them that you value every day that they have and will help them access anything they need to enjoy that time.

SR is an eight year old with a brain tumor. His parents were told at the time of diagnosis that he had one month to live without treatment, and six months to live with treatment. (This may not be exactly what they were told, but this is what they heard). The family decided to enroll their son in hospice rather than treat him. We discussed symptom management at length and suggested palliative radiation. As of the date of this article, nine months have passed since his diagnosis. He has traveled to Disney World with his family, attended family summer camp for kids with cancer, and is deciding if he wants to attend another summer camp.

Not all of our patients die.

One out of six hospice patients are discharged from Montgomery Kids. We don't ever know for sure that a child will die in the next three months, and we don't expect referring clinicians to know either. Some of our patients stabilize the trajectory of their illnesses and no longer need our help. We're happy to discharge families to life. They know that we're here for them if they should need our help again.

WJ is a baby who was diagnosed with trisomy 18 prior to being born. Many infants with trisomy 18 are stillborn. We met with the family prior to delivery and developed a birthing plan to include the parents' wishes that their child would not suffer. After birth, we supported the family with biweekly in-home visits instructing them on feeding and managing any distress. After four months, she was discharged from our service and is now being cared for by a primary care pediatrician. She has a life-limiting illness so we will continue to keep in touch with her and monitor closely if she should deteriorate. If she needs us in the future, we will be there for her and her family.

As a primary care physician, I know how much you care about each one of your patients. As a hospice physician, I can guarantee you that the Montgomery Kids team will also care for any child that you refer to us. We will work with you and the child's family to allow that child to continue to live during the time that they have left.

Dr. Caren Glassman
Montgomery Kids Physician



Caren Glassman, M.D., is a board certified pediatrician and fellow of the American Academy of Pediatrics. A native of Montgomery County, she completed her training at the George Washington University School of Medicine and Georgetown University Medical Center. Dr. Glassman is a cofounder of Potomac Pediatrics, PC in Rockville, Maryland and a staff physician for Montgomery Kids. She is committed to revolutionizing the way we approach illness in children.