

Transition Planning for Young People with Brain and Spinal Cord Tumors

By Rebecca Mannis, PhD, and Patty Weiner, MS, CCLS, Education Specialists, Making Headway Ongoing Care Team

As more and more children survive brain and spinal cord tumors well into adulthood, they and their parents increasingly face the challenges of planning for their ongoing education and entrance into the world of work. Many of these children face lifelong intellectual challenges that are fundamentally different from more common learning problems such as dyslexia, and these challenges can be difficult for parents and schools to understand.

Even the most intelligent children who have brain and spinal cord tumors commonly have difficulty with certain brain functions. These include executive functioning (organizing and planning), processing speed and memory. To complicate matters, processing and memory problems tend to become worse as children and young adults are asked to learn and apply new information. These difficulties may also become gradually more evident as children mature and are expected to become increasingly independent.

What is Transition Planning?

Good transition planning generally begins with a consideration of the child's intellectual abilities and skills as well as his or her capacity to deal with transitions, organize tasks and juggle personal and work responsibilities. The child, his or her parents and the experts they work with then use this information to consider what might be appropriate educational and vocational/career goals, and how the child can be best assisted in reaching these goals. One important aspect of this is deciding what kind of high school diploma makes the most sense—academic or vocational?

How and When Should Families Think about Transition Planning?

The Individuals with Disabilities Act, which was revised and reauthorized in 2004, now includes several requirements to ensure that public high schools provide better transition planning. However, how thoroughly these requirements are met varies by school district, and many savvy parents have come to realize that transition planning often begins too late. The success of transition planning also depends on how well parents are able to advocate for their children and partner with the schools, as well as on the amount of guidance they are able to find from experts in the process.

Individual Education Plan (IEP) meetings (legally required for children who have been given an IEP) are good opportunities to discuss transitional issues. As members of the IEP team, parents can suggest that the child's services include life and advocacy skills early on, rather than at 16, the traditional age for beginning these services. While more immediate academic or behavioral problems sometimes make it hard to focus on this kind of advance planning, families should remember that the more time they have to evaluate and implement a long-term plan, the better. After all, what can be more important than a child's future?

The Making Headway Ongoing Care Team can help families locate an expert to consult with them about long-term planning. Call our office at (914) 238-8384 or send an email to info@makingheadway.org.

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Below: Sanbesh Henry with his sister Anita.



A Foundation Dedicated to the Care, Comfort and Cure of Children with Brain and Spinal Cord Tumors.

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Top: Maya Manley with Lily Langbein.

Bottom: Maya Manley with Sharon, Cherraine and James Davis on the Jewel cruise.



Supporting Families on a Difficult Journey

A Message from Maya Manley, Founder and Secretary

Three years ago, when we moved from Beth Israel Hospital to the new Hassenfeld Children's Center Day Hospital at New York University Medical Center, it was not simply a matter of changing our location. It is never easy to integrate one program into another, but with the encouragement of Dr. Jeffrey Allen and the full support of director Dr. William Carroll and his caring and competent staff, Hassenfeld has become an even greater haven for families.

In fact, Dr. Carroll, who shares our beliefs, has become a trusted partner. One of his main objectives is to promote wellness for both children and parents. We are pleased to have been able to help him in several ways. We fund the work of Gunilla Asp, a Swedish massage therapist, who sends parents and children out of the massage room simply glowing with serenity and calm. We also fund Annie Hickman, an extraordinarily gifted yoga teacher. And we continue to provide nutritious food in the playroom, to satisfy the children's hunger after long sessions in the MRI machine or simply waiting to see their doctor.

Every family that enters the playroom has its own complex story, and every child is unique. Some children are scared or depressed, or hold difficult emotions tightly inside to protect their discouraged parents. Others bound into the room, eagerly taking up arts and crafts projects, playing music, or catching up with Dr. Allen and his nurse Erin when they drop by.

Of course, parents are also unique, but they share many traits. The news of their child's illness is always a devastating blow. On top of their worries about their child's outlook, they may be worried about their jobs or their health insurance coverage. This is why we must be there for them and their children a thousand times over, surrounding them with all the love and support we can muster. It is our goal to send them home at night with renewed strength and hope, proud of their children who have endured a difficult time with courage. This has always been the mission of Making Headway.

Twenty-five years ago, when our daughter Cynthia was diagnosed with a brain tumor, our family had nowhere to turn for help and advice. It was this experience that led us to found Making Headway, hoping to support other families on the same difficult journey. It is always my greatest wish that parents take full advantage of the services Making Headway provides free-of-charge. Support far beyond the playroom is available; no one need feel alone in the days and years after leaving the hospital. To access our exceptional team of psychologists and educational remediation specialists, simply contact our office and Dr. Marcia Greenleaf, the Ongoing Care Team Coordinator, will get in touch with you. Help on this challenging journey is just a phone call away.





Legal Questions?

Attorney Karey McDonough is Here to Help

When Karey McDonough was in college at Georgetown, she got a part-time job assisting the in-house counsel at the hospital there. The lawyers were all former nurses who had returned to school to take up health care law, and it was an exciting, inspiring place to be. By the time she graduated, Karey knew what she wanted to do. She enrolled in both Georgetown University Law Center and Johns Hopkins School of Public Health, finishing with a joint degree. Then she joined a corporate law firm and honed her skills as a health care attorney.

Today, Karey divides her time between her two young boys—just 1½ and 3 years old—and her work for Making Headway. When she picks up the phone in her home office in Virginia, she never knows what challenge awaits her. It might be a parent who is overwhelmed with the paperwork involved in applying for disability insurance or supplemental security income. (“It’s a lot of bureaucracy,” explains Karey, “You have to make sure you check the right boxes, say things just the right way, or they can deny you benefits.”) It might be a distraught family member holding a letter from a health insurance company, stating that coverage for their child’s critical procedure has been denied:

“I help families figure out how to appeal—I know what the insurance company probably needs to hear in order to approve coverage. I write the appeal, or I give them feedback on what they have written. Sometimes I even pick up the

phone—there’s nothing like a call from an attorney to turn around a decision.”

Families report that Karey’s help is invaluable, and the best part of it is, she’s part of the Making Headway team, and families use her services free-of-charge. From Karey’s perspective, it’s a win-win situation, too. With a growing family, part-time work is useful, plus it helps her to keep her skills sharp. And it’s a welcome relief after the corporate world. In fact, Karey reports that when she’s ready to go back to more full-time work, it probably won’t be in a corporate setting:

“Working for Making Headway has been an eye-opening experience for me. I love to feel like I’m helping people directly, and I’d like to continue to do that. After all, that’s why I went into health care law in the first place.”

If you need the services of a health care attorney, contact the Making Headway office at (914) 238-8384, or send an email to info@makingheadway.org.



Top left: Karey McDonough with her sons.

Above top: Hassenfeld volunteer Renee Etra with Nicholas de Laurentis.

Above bottom: Paula Santiago dressed up for western day at Hassenfeld.

Amanda Roussel with Hassenfeld child life art therapist Kim Tabatt-Haussmann and social worker Laurny Weinshank.



Families Who Have Not Forgotten

About 250 people showed up on a beautiful evening to admire the flowers and breathe in the spring air at the tenth annual “*All-is-oneE*” **Tulip Festival Dinner Dance**. Sponsored by Jeannie and Greg Trunz, who donated the facilities of the elegant Swan Club, this year’s event honored Maya and Edward Manley and their children for their ten years of service. The delightful affair raised \$140,000 for Making Headway.

A couple of hundred men, women and children ran, walked and pushed baby strollers on a lovely spring day in Point Lookout, New York. The occasion was the ninth annual **Little Bit of a Walk and Fun Run**. Organized by Diane and Pat Ryan, the pledge-based event brought in \$33,200 for research, including over \$6,000 raised by students from Valley Stream South High School.

The fairways were crowded with generous-minded sports enthusiasts at two recent events. About 100 golfers showed up to play, dine, buy raffle tickets and outbid each other on tempting auction items at the third annual **Kyle A. McKay Golf Classic**, hosted by Lauren and Don McKay. The event, held at the Crab Meadow Golf Club on the north shore of Long Island, raised \$31,000. And another hundred people tried for par at the Van Cortland Golf Course in the Bronx, participating in the fifth annual **Nicky Docu Memorial Golf Tournament**. Guests finished off the day with a barbecue and another silent auction, and Making Headway benefited to the tune of \$15,300. The event was hosted by Christine and Tom Docu.

If you’ve been anywhere near Westport, Connecticut, recently and wondered about all that music in the air, you might have been hearing the sounds of giving. Young participants in Teri and Mark Gaberman’s **Aaron Gaberman Practice-a-Thon** raised \$2,037 while improving their musical technique. The event was organized with the support of the Suzuki Music School of Westport.



Gracious Giving

Throughout the year, Making Headway receives numerous gifts from individuals, families and friends, organizations and companies. These gifts help us fulfill our mission. No matter how great or small, we are honored by each contribution and sincerely thank you. Some examples of gracious giving include the following:

Lots of kids have been busy recently, raising money, raising hope, and demonstrating that there is no minimum age for caring:

- For the third year in a row, Valentine’s Day took on a special meaning at **Tyler Epple’s** school, **Abbey Lane Elementary**. The children there held their annual “Hearts of Hope” fundraiser, purchasing and papering the walls with signed cut-out hearts, and in the process raising \$191 for Making Headway.

- Nine-year-old **Lauren Lam** and a friend combined creativity and entrepreneurship, making colorful foam buttons and selling them to friends and family. The admirable project brought in an impressive \$300 for Making Headway.

- After dozens of nutritional bars failed to sell at a local yard sale, neighborhood children **Angelica Richter, Scott Martin** and **Nicole Kleet** took matters into their own hands. The three youngsters went door-to-door with the tasty goods, then surprised five-year-old **James Stanton** and his family by presenting them with the proceeds—half for James, and half—\$51—for Making Headway.

- When **Jake Capello’s** brother **Josh** was in treatment, Jake was welcomed right alongside him in the playground, joining in the fun and treats. Not only has he not forgotten, but he’s anxious to ensure that siblings continue to receive this regal treatment. So for his first communion, Jake asked family members to donate money in lieu of gifts, raising \$300 for Making Headway.

When it came time to plan their wedding, **Regina Garone** and **Frank deMarco** didn’t forget about others in need—including Regina’s own cousin, **Lea**. In lieu of wedding favors, the couple donated \$400 to Making Headway. Best wishes—and many thanks—Frank and Regina!

And congratulations to **Anne** and **Michael Martin** on 50 years of marriage! They, too, made the day special by asking that friends direct gifts to Making Headway in honor of their grandson, **Timothy**. The couple raised a grand total of \$1,900.

Friends and family responded to the loss of their beloved **Sara Chaikin** with an outpouring of donations in her memory, of which \$2,143 benefited Making Headway.

And for the fifth year in a row, about 140 Making Headway family members enjoyed a relaxing cruise on the S.S. Jewel, including a delicious lunch and some truly spectacular views. Thank you five times over to the generous sponsors of this event, **Marisa** and **Richard Stadtmauer**.

Top left: Greg Trunz with Maya and Edward Manley at the Tulip Festival Dinner Dance.

Bottom left: Students from Valley Stream South High School at the Little Bit of a Walk fundraiser.



Above: Lauren Lam (far right) with her dad Richard and her sisters Shannon and Katie.