# Hello from the other side

## Parental reflections on the patient-parent–family physician triadic relationship

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As parents of medically complex children, we have had many experiences interacting with family physicians and the health care system. We have seen first-hand what timely, supportive, and collaborative relationships with our family physician can accomplish in terms of promoting health and minimizing unnecessary office and emergency department visits. We have also experienced troubling moments when our experience and suggestions were ignored, which resulted in subsequent delays in addressing health care needs. This brief reflection will explore 4 issues central to effective collaborative working relationships among the patient-parent–family physician triad when the patient has an intellectual and developmental disability (IDD): consistent involvement and mutual trust as the basis of collaboration; respect for the expertise of parents; acknowledgment of the mingled relationship between a parent and an adult child with IDD who is nonverbal; and the importance of attending to the needs of parent caregivers.

We are parents of children with IDD. The first author (L.M.) is trained as an occupational therapist and is currently a doctoral candidate. Her 18-year-old son, Matthew, lives with an IDD in the profound range and level V cerebral palsy. He is nonverbal, has a history of seizures and breathing difficulties, and is maintained on a feeding tube. For the purpose of this reflection, we explore a recent clinical encounter involving Matthew, as shared by his mother. The second author (J.M.) is a family physician and parent of an 11-year-old girl, Katie, with an IDD in the severe range associated with level V cerebral palsy, epilepsy, tube feeding, and food allergies. We believe this vignette demonstrates an effective collaborative triadic relationship and illustrates our 4 main points.

> Last week Matthew developed a nasty upper respiratory tract infection. By the fifth day, he was running a low-grade fever and was showing a gradual decline in oxygen saturation measurements, which were now running as low as 90%. From experience, I recognized that his lungs were clear and his respirations were not laboured, so I knew not to panic. But the downward trend of his oxygen saturation was making me nervous because several months earlier Matthew had been rushed to hospital and admitted to the intensive care unit following a similar rapid decline in his oxygen saturation. I was fortunate to be able to talk to my son's family physician. During the telephone conversation, we were able to establish a plan that addressed both home-care strategies and also when to take Matthew to the hospital. Thankfully, he recovered at home and did not require a hospital assessment or admission.

Ms MacGregor's son, Matthew.

Dr Martin's daughter, Katie.

### Consistent involvement and trust

The physician-patient relationship is central to the role of the family physician. However, in cases involving medically complex children, a team of specialists and multidisciplinary team members often manage the child's ongoing care. The patient and parent work with a dizzying number of health care providers who change as the child ages or as the child's condition evolves. In this vortex of multiple relationships, the family physician plays a crucial role by providing a consistent source of medical support and advice. This becomes particularly important when patients with complex care needs transition from pediatric to adult care. The above vignette occurred shortly after Matthew aged out of pediatric care. The family physician's ongoing involvement in his medical journey allowed her to seamlessly enter the ensuing medical situation.

The fact that the family physician provided primary care to everyone in Matthew's family enhanced the collaborative relationship between her and L.M. This relationship preceded Matthew's birth. The family physician had subsequently provided support to L.M. during her many difficult moments of parenting her child with IDD. Similarly, the family physician had cared for Matthew during minor illnesses and had contributed as a member of the health care team during life-threatening crises affecting him over the course of his 18 years. This almost 2-decades-long triadic relationship allowed L.M. and her family physician to develop a deep sense of trust in each other's contributions to

Matthew's health care. The family physician encouraged L.M. to take an active role in the medical management of her son's health care, knowing that she would not consult physicians without a good reason. Correspondingly, during a crisis, L.M. could be assured of rapid access to the family physician or another member of the practice group to identify when hospital or specialist assessments and support were warranted and to help her to interpret the results.

The family physician further acted as an important resource to help L.M. to navigate the complex health care system by organizing necessary referrals and working collaboratively to determine clear goals and plans for Matthew's health care. This long-standing collaborative relationship ensured optimal medical care for Matthew, while minimizing the anxiety and burden that any parent caring for a child with complex medical needs experiences.

## Respecting the expertise of parents

We both have academic and clinical backgrounds in the health sciences; however, it is important for family physicians to remember that all parents of medically complex children develop extensive knowledge about their children's health conditions over time that can help inform their children's health care. However, we have both had numerous experiences of physicians ignoring our assessment of our children's health status, to the detriment of our children.

Through her many years of working with Matthew's mother, his family physician could trust L.M. to provide relevant and accurate reports about her son's condition. As a result, the physician actively sought and carefully considered L.M.'s understanding of any emergent situations involving her son. This mutual acknowledgment of expertise, and particularly the family physician's appreciation of and willingness to leverage the parent's expertise, ensured that timely and effective plans for Matthew's care could be established.

## Acknowledging the mingled relationship between a parent and an adult child with IDD who is nonverbal

Years of parenting children with complex health care needs enables many parents to identify with and develop a "sixth sense" about their children's bodies, to the point sometimes of feeling the child's pain. We think of this enmeshed bodily relationship as a form of porous bodies and mingled voices. This phenomenon is normal, indeed inevitable, and can be helpful in informing decisions regarding the best course of health care for an adult patient with IDD who cannot answer questions, respond to commands, or participate in a medical assessment in any way. Family physicians should acknowledge that parents can be accurate in their understanding of their children and their children's health needs and concerns. On the other hand, family physicians should be attentive to when a parent's voice might reflect the parent's own distress rather than that of his or her child. For example, sometimes parents' natural anxiety concerning their children can lead them to be hypervigilant or overprotective of their adult children and, consequently, to seek health care when it is not warranted or to limit health care when it is warranted. These instances can usually be detected by the family physician and addressed if the family physician–parent-patient triadic relationship is strong.

## Attending to the needs of parent caregivers

Parents who care for adult children with complex health needs often live on the proverbial edge. That is, these parents cope with a range of chronic physical, mental, financial, and environmental pressures. Full-time caregiving can be an enormous burden on parents that can have times of relative calm interspersed with episodes of considerable stress. In the triadic patient-parent-physician relationship, the family physician is the care provider for both the parents and their children over the life course. Family physicians should understand the importance of various stages of the life course and various life events in attending to the needs of both. For example, the family physician should be aware that unemployment, marital discord, illness within the extended family, and other stresses can affect the health of the whole family. During appointments, the family physician should engage a multilayered, holistic assessment of the caregiving picture and offer appropriate supports. In the vignette presented, it is fortunate that the physician has known the entire family for more than 20 years. This means that, even during appointments focused on the son's health, the family physician always takes time to monitor the health and well-being of L.M. and other family caregivers and can intervene as appropriate. For example, the family physician knew that during an acute medical crisis, such as the one noted here, L.M. tends to cope well, but will often "crash" a few weeks later. As a result, the family physician would initiate some sort of contact with L.M. after such a health crisis to ensure that she is coping.

## Concluding thoughts

Often, L.M. affectionately refers to her "inner mother bear" as *Fang*. Fang is maintained on a very tight leash and is only released when she feels her child's health is at risk. In fact, she can think of only 2 occasions over the course of Matthew's 18 years when she unleashed Fang. In both situations, a physician ignored her assessment of Matthew's presentation, and he suffered as a result.

Part of the reason Fang lies dormant in her cage for years on end is because L.M. has a long-standing, mutually respectful, supportive relationship with her son's family physician. This physician has remained a

consistent figure in Matthew's care, allowing her and L.M. to develop a strong working relationship over 18 years; she also respects L.M.'s expertise gained from caring for Matthew and actively solicits her involvement and input in all medical situations. She appreciates the deep bond between her patient with IDD and his mother, and harnesses this intimate connection in order to assist her understanding and assessment. Because the family physician treats L.M. as a valuable member of Matthew's health care team by soliciting her input and carefully considering her suggestions, she was able to assess the situation in our vignette accurately, establish a plan to address his declining oxygen saturation, and keep Matthew comfortably recovering at home. However, both parent and physician were also comfortable with the fact that a clear plan had been established should his condition deteriorate. The highly effectively triadic relationship among patient, physician, and caregiver ensured that Matthew avoided unnecessary trips to the physician's office and to the hospital.

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**Competing interests**
The authors are parents of children with intellectual and developmental disabilities.