

IN THEIR OWN WORDS

Alice Twombly

Three years ago, my son was born with moderate hypospadias. We consulted two pediatric urologists in Boston. Both were very informative and educated me about the surgical treatment of hypospadias. I learned that, for the most part, hypospadias surgery has a very good surgical outcome. However, neither of the doctors could tell me what the psychological, social, or emotional consequences were of living with hypospadias. Neither could they give me any supportive information on how to raise a son with hypospadias. As a concerned parent (and having some nursing education), I searched the medical literature for any information that would prepare my husband and me for raising our boy. I found very little information about the psychosocial and emotional aspects of hypospadias in the literature.

Turning to the Internet, I found parents, men and professionals sharing perspectives on their experience of hypospadias. All report some degree of impact on their psychological, social and emotional states. A common theme among the stories from parents of newborn hypospadiac boys was that of a lack of initial education regarding the diagnosis. Concerns of teens and young men were most often those of sexuality and lack of historical information regarding their condition. Adult men expressed themes of inadequate knowledge regarding the aging hypospadias repair and its potential for breakdown. Overwhelmingly, most commonly referenced theme by parents and men of all ages was one of isolation.

I offer a collection of these anecdotal stories to the professional medical community. I believe that they will enhance the understanding of hypospadias and its lifelong implications to parents and men. I am greatly impressed with the surgical advances in the treatment of hypospadias and other variant genital conditions. I hope to see similar advances in the psychosocial and emotional care of these conditions.

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