

"If you build it...": Creating an adequate support system to transition the care of pediatric patients with spina bifida into adulthood

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Cite as: *Can Urol Assoc J* 2016;10(9-10):313. <http://dx.doi.org/10.5489/cuaj.4091>

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In the 21st century, it is generally expected that children born with spina bifida will not only survive into adulthood, but in many cases will be contributing members of society. This optimistic view has been the result of decades of improvement in the management of this condition in childhood, often via coordinated multidisciplinary care teams. Given that so much effort is invested in the care of children with spina bifida, it only makes sense that we healthcare providers and society at large do all that is possible to protect this investment. Since the main urologic manifestation — the neuropathic bladder and various sequelae related to it — is a life-long risk factor that can lead to complications at any age, these patients require ongoing support as they transition into adulthood.

So why doesn't this universally occur? There are likely multiple reasons, but none that are insurmountable. There must be healthcare providers with the knowledge, skills, and interest to manage the urological issues of these patients. The first two items should now be an expectation of every graduate from a urology residency in Canada, since they should be seeing this patient population in all age ranges during their training. Interest is another matter; and the creation of a Spina Bifida Treatment Network (SBTN) to support community urologists in their management of these patients would be a major step in facilitating this outcome.¹

Another solution, which is not mutually exclusive, is to use the pediatric model of multidisciplinary clinics to create similar care teams dedicated to adults with the condi-

tion. I believe in the "Field of Dreams" adage that, "If you build it, they will come." In fact, this has been our experience in Nova Scotia. We created an adult multidisciplinary clinic (urology, neurosurgery, psychiatry, nursing) more than 15 years ago, and it now has a larger patient roster than the original pediatric clinic from which it grew. In a recent review of our experience in this adult clinic, we reported that urological issues are exceedingly common, occurring in 88.5% of our patients at some point during their followup.² Furthermore, 81% of these issues required urological intervention. We noted that 50% of urological problems requiring treatment occurred within a 24-month period, indicating that the ideal followup interval should be at least that frequent.

If, as suggested by Koyle et al,¹ there is a genuine "focus on individuals and families," then we will have an excellent chance to do the right thing: create a support system that builds on the successes of the past decades in the pediatric realm to provide equally successful adult healthcare for this unique patient population.

Competing interests: The author reports no competing personal or financial interests.

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