

Self Infusion: Achieving Independence With The Added Challenge of Autism

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OBJECTIVES

- Approximately 1 in 50,000 boys live with Hemophilia B worldwide (CHS, 2008), and 1 in 68 live with autism (Autism Nova Scotia). Some live with both, making independence difficult. Many with autism also suffer from anxiety and difficulties with social interaction, communication and learning (Health Canada, 2013). Those with autism have a need for “stability, routine and sameness” (Autism Nova Scotia).
- Adam is a 27 year old male with severe hemophilia B, autism and anxiety. His autistic characteristics include echolalic language, wringing of hands, and knuckle cracking when nervous
 - Prophylaxis: 2x/week, infused by parents at home since age of 4
 - Spring 2013: Adam requested to learn self infusion
- **Goal:** to determine the best and most effective way to teach this young man self infusion in light of added challenges

METHODS

- “Be involved Program” was introduced by Pfizer Canada in spring 2013. It was created to “help Canadian patients in the management of Hemophilia” (Pfizer, 2013), and designed to “assist Hereditary Bleeding Disorder Clinics to expand and customize support for patients when additional aid is required” (Pfizer, 2013).
- Four main parts: Be Empowered, Be supported, Be prepared, Be informed (Pfizer, 2013).
- Adam was a perfect candidate for the “Be supported” arm of the program. His instruction and support took place in his home environment.
- Simple application process
- First visit: assessment of comprehension and readiness to learn. Routine and attention to detail were noted to be important to Adam.
- Tool box of supplies-put together as a child and was still being used today
- Total of eight home visits over 3-4 month period
- “Homework” task was given after each session

RESULTS

- “Be involved “ program allowed Adam to learn at a pace comfortable for him, and allowed for teaching to be done in a setting that was familiar and conducive to his routine
- After eight home visits Adam began infusing his own Factor IX with minimal assistance
- “Be involved “ allowed for a successful experience for Adam
- Follow up several weeks later: Adam continues to self infuse. He is self-confident and pleased with himself!



CONCLUSIONS

Learning self infusion can be a challenging task; however, even those with added considerations like autism and anxiety can overcome the hurdles of an undertaking such as this if given the best environment and conditions. For those with autism a supportive, patient-focused, and predictable routine is crucial for a successful teaching program. The “Be Involved” program gave Adam this opportunity by allowing him to learn self infusion in the safe environment of his own home.

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