



HEALTHCARE TRANSITION IN THE HYDROCEPHALUS COMMUNITY

Each year, 5000-6000 hydrocephalus patients are left with the task of transitioning out of the pediatric healthcare system. This transition requires patients to identify a new care team of providers that include primary care physicians, neurologists, and neurosurgeons that will satisfy their complex medical needs.

Despite the large number of patients who make this transition each year, many experience significant barriers that affect the ability to receive care. These challenges include:

- **Inadequately Planned Health Care Transition Coordination:** Although there are some programs offered specifically for hydrocephalus patients, most lack access to them. Families spend large sums of money and time as a result. This grueling process may create strong feelings of isolation and anxiety.
- **Difficulty finding an adult neurosurgeon:** Many patients may struggle when trying to identify adult neurosurgeons who can meet their complex needs. Few neurosurgeons show interest in taking them as patients due to reimbursement challenges and lack of education. Unlike pediatric neurosurgeons, most adult neurosurgeons lack adequate training to care for adult hydrocephalus patients. The Relative Value Unit (RVU) metric, that calculates reimbursement costs for providers, has been shown to undercompensate evaluation and management services, which are common for hydrocephalus-related care. The transition period may take years due to provider disincentives.
- **Lack of coordination between Health Care Professionals:** Transitional care must include collaboration between relevant HCPs. The majority of neurosurgeon practices are not designed to care for adult hydrocephalus patients. Neurologists, who have stronger expertise on caring for neurologically complex patients, must be integrated into care regimens to ensure patients' needs are taken into account. Coordination between providers can strengthen prevention efforts and lessen the likelihood of medical emergencies for hydrocephalus patients overall.
- **Research Challenges:** Minimal research exists on the healthcare transition of youth hydrocephalus patients. It is unclear which federal agencies, if any, account for these common challenges experienced by medically-complex patients. The current gaps make it difficult to assess the efficiency of current transition programs.

The lack of proper care infrastructure for patients has been described as a **"care cliff"**. As individuals phase out of the pediatric system, they are left with no roadmap on how to effectively navigate their care. As a result, patients may stay with pediatric care providers for extended periods of time. The patients who are unable to stay with their pediatric physicians are left with the grueling task of searching for adult providers who may be located in other cities or even states.

New forms of medical innovation have allowed pediatric hydrocephalus patients to live long and fulfilling lives. These care advancements underscore the need for strong forms of infrastructure that help facilitate the transition of pediatric patients to the adult healthcare system. New programs and forms of care are essential in guaranteeing a better process for patients with complex health challenges within the American Healthcare system.