

FALL, 2012

ON THE uptake



L'Hôpital de Montréal pour enfants
The Montreal Children's Hospital
Centre universitaire de santé McGill
McGill University Health Centre



GROWING UP WITH CEREBRAL PALSY: PLANNING TRANSITION INTO ADULTHOOD

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Cerebral palsy (CP) is the most common cause of physical disability in children, affecting about 2 to 3 people out of every 1000. In more vulnerable groups such as children born prematurely, there are an even greater number of individuals with a diagnosis of CP. Although CP is defined as a non-progressive motor disorder, it is superimposed on the dynamic processes of development and aging and most individuals with CP live well beyond their 18th birthday. Adults with CP require ongoing health services to monitor and address persisting needs that were present in childhood. Feeding difficulties, gastroesophageal reflux, constipation, seizures, progressive scoliosis, contractures and dislocations secondary to spasticity continue to be important medical issues to address. Access to routine health and dental care and screening are also important, and may include, for example,

cardiovascular health, pap smears, mammographies, and health needs related to sexuality and lifestyle habits.

There are also many new health issues that emerge in adulthood: overuse syndromes, chronic pain and fatigue, osteoarthritis and osteoporosis, and overall decline in health state. However, access to healthcare once individuals are of adult age can be challenging. Typically, individuals with CP and their families can experience difficulties finding a primary care physician or have reduced access to interdisciplinary care and rehabilitation services. This can result in fragmented and sub-optimal care. Furthermore, contextual factors (personal, environmental) can play a big role in the individual's quality of life. In particular, aspects of family functioning, behavioural difficulties and motivation are important predictors of social-emotional adaptation and well-being. These factors among others should also be targeted in transition planning.

Transition challenges:

Most institutions and hospitals transfer patients with CP to adult care rather than transition them. *Transfer* is the actual responsibility of care of the patient being moved from a paediatric setting to an adult care setting, usually by 18 years of age. *Transition* is the "purposeful, planned preparation of patients, families and caregivers for transfer of a patient from a paediatric to an adult care setting" (from the 1993 Position Paper of the Society of Adolescent Medicine). Transition is a *process* that should ideally start at 12 years of age and is a priority mandate for those caring for youth with special health care needs. The key challenges in transitioning young adults with CP are common to all individuals living with chronic disabilities having special health care needs. The individual's maturity and cognitive ability, the preparation of the patient and family, and access to specialists and interdisciplinary care as adults are but a few of the key issues.

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Although most Canadian medical institutions require transfer of care at 18 years, it is well accepted that age is not the best indicator of preparedness. The individual's maturity and cognitive ability are important factors to consider, and preparing individuals within a developmentally appropriate process to become increasingly autonomous in their interaction within their health care environment is encouraged. Examples of skills to develop include making appointments, taking medications, and actively participating during medical visits. Individuals with significant cognitive impairment, who will continue to be fully dependent as adults, will need additional consideration for proxy decision making, legal guardianship and estate planning. Youth and young adults with CP and families need to be informed on their medical condition, their medications and side effects, self-management skills, and how to navigate the adult health care system. It is especially important for individuals with CP and their close family members to know their medical history when faced as adults with the reality of aging parents and new health care professionals who are unfamiliar with them. The transition process should focus on preparing for a life course, "living well" with a chronic disability and optimizing their full intrinsic potential and well-being.

Although ensuring the continuity of healthcare, with routine preventive care, dental care and rehabilitation services is a focus within medical establishments, individuals need to transition in other spheres that are equally important. These include education and employment, finances and benefits, housing, transportation, leisure activities and relationships. Without preparation, families and paediatric healthcare professionals can be reluctant to transfer adolescents with CP to adult care at a critical time when youth are undergoing many transitions in their life that create

multiple personal and familial challenges. Paediatric and adult healthcare environments have traditionally been quite different in their approach, with paediatric care being more family-centred and paternalistic. Parents worry that their concerns about their child's health will not be addressed in the adult milieu, and that they will no longer be able to advocate effectively for their adult children or navigate an increasingly fragmented health care system on their child's behalf. There is also a bond with the paediatric healthcare professional team who has known the family from the time of initial diagnosis. Finding a primary care provider can be challenging, yet primary care providers are instrumental in coordinating their care. An interdisciplinary care environment is optimal for adults with CP, where a coordinated multifaceted team approach helps avoid multiple trips and fragmented care. Improving the knowledge and comfort level of adult care providers in treating young adults with CP through education may be of benefit. Adults with CP also see their access to rehabilitation services progressively diminish over time. D. Nancy Young and colleagues in Ontario interviewed teens and adults with cerebral palsy, spina bifida, and acquired brain injuries of childhood, and their parents, asking them to identify barriers to transition and to propose solutions. The top four barriers were:

- lack of access to healthcare
- lack of knowledge by professionals
- lack of information provided
- uncertainty regarding the transition process

Two simple solutions highlighted were more information and more support throughout the transition process.

Models of transition:

As previously noted, transition is a process incorporating the developmentally appropriate preparation of the patient within their family unit for their eventual transfer to adult care. Effective transfer of patients necessitates communication between healthcare workers across institutions and sharing of information. This information exchange goes beyond a simple transfer summary, which may not be obtained in time and often lacks details of previous investigations and the functional status of the patient. Maintaining an up-to-date record of their medical history should ideally be done early and over time to avoid delays or gaps in information exchange. The Good2Go Transition program at Toronto's SickKids Hospital advocates the use of MyHealthPassport for this, which can be completed online and printed (<http://www.sickkids.on.ca/myhealthpassport/>). Patients with CP can be transferred to a number of different clinical environments: a primary care clinic, a general adult neurology clinic within the community, a subspecialty clinic if available, a rehabilitation centre, or a joint paediatric and adult healthcare provider clinic. These joint clinics are increasingly favoured within various subspecialties, where both the paediatric and adult healthcare professionals involved initially see the patients jointly to ensure a smooth transfer of care. However such clinics may not be feasible within most busy practices and may be limited in number and less accessible to those living outside urban centres. An overlap in care by returning to see the paediatric care provider after the initial adult care visit may be a reasonable option, ensuring that there is no gap in care and providing the family with any needed additional resources within their community. Several transition checklists are readily available in the literature and online which can be

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adapted and used clinically at various ages.

Two great programs with accessible resources online include:

- 1) The Good 2 Go Program at SickKids Hospital in Toronto: <http://www.sickkids.ca/Good2Go/>
- 2) The Health care Transition Initiative University of Florida, Institute for Child Health Policy: <http://hctransitions.ichp.ufl.edu/>

The important elements of the transition process are to start early and plan ahead, prepare for a life

course service model, and involve families in the process so as to ensure that their needs and concerns are addressed. Benefits of a transition program for individuals with CP include a better continuity of care and information-sharing between paediatric and adult care providers, improved patient care and education, and potentially reduced long term health care costs. It also provides physicians and trainees with an educational opportunity to learn about the process of evolving care of adults with CP, with the hopes of inspiring some adult care providers to specialize in the care of this expanding adult population.

Take away points

- The transition process to adult care for individuals with cerebral palsy necessitates communication and information sharing between healthcare workers across institutions.
- The transition process should focus on preparing individuals for "living well" with a chronic disability and optimizing their full intrinsic potential and well-being.
- Access to healthcare for adults with cerebral palsy can be challenging. Contextual factors – both personal and environmental – should be targeted when planning a developmentally appropriate transition to adult care.
- An interdisciplinary care environment is optimal for adults with cerebral palsy, where a coordinated team approach helps avoid multiple trips and fragmented care.

TRANSITION FROM PEDIATRIC TO ADULTHOOD HEALTH CARE FOR YOUNG ADULTS WITH NEUROLOGICAL DISORDERS: PARENTAL PERSPECTIVES

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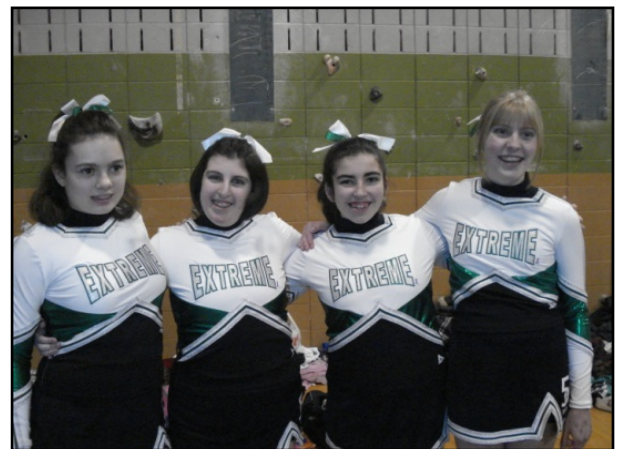
The movement toward adult health care services is an expected and desired outcome of pediatric care. When the transition of care involves a young adult who has an intellectual impairment in addition to a complex chronic neurological condition, parental involvement is crucial. As these young adults are unable to make informed decisions independently, they require significant guidance from their parents.

In order to appreciate parents' perceptions of their young adults' transition process, 17 parents of 11 young adults who had transitioned to an adult health care setting were interviewed. The findings from these interviews suggested that parents perceived a tremendous sense of abandonment from the health care team during the transition process. They experienced a sense of loss, fear

and uncertainty. Parents believed that what hindered the transition process was a lack of sufficient coordination, the vulnerability of the young adult at the time of transition (for example if the young adult was experiencing an illness), the lack of appropriate resources in the adult health care system given the unique and multifaceted needs of the young adult and their own tenuous health status (whether the parents themselves were not well). Parents felt that what did help them through this process was their own resourcefulness, their family's support and their ability to gradually develop new relationships within the adult health care setting.

This study showed that the emotional toll on parents during the time of transition is tremendous

and requires thoughtful consideration by health care professionals when planning the transition process for these young adults. Although parents acknowledged the hardships and adversity that they faced during the process was immense, they felt that with better guidance and improved resources, the experience for future families could be a positive and satisfying experience.



Young adults with disabilities care about optimizing their full potential and well-being.

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