

### The transition from childhood into adulthood – a challenge in living with cerebral palsy

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The number of people living with cerebral palsy (CP) continues to grow, largely due to increased survival of low-birthweight infants and improved life expectancy. Despite extensive research and impressive progress in medical care, there is still no intervention that can reverse the brain injury causing CP. The focus of care in CP is therefore on appropriate combinations of interventions to improve overall function and participation in the community in childhood. Although CP is defined as a non-progressive disorder, it is accompanied by secondary disturbances which need life-long medical care.<sup>[1]</sup> The question many parents face is, 'Where do you find support for your child with CP when he/she gets older?'

Over the last couple of years our research group has studied the well-being of adults with spastic diplegia living in South Africa (mostly based in the vicinity of Cape Town). The initial studies focused on adults who received the neurosurgical procedure selective dorsal rhizotomy (SDR) more than 15 years ago<sup>[2]</sup> and who were able to show the positive results of SDR in their level of functioning,<sup>[3]</sup> walking ability,<sup>[4,5]</sup> spinal abnormalities<sup>[6]</sup> and participating in the community.<sup>[7]</sup> We then evaluated adults with CP who had only received orthopaedic interventions in childhood.

One of the most striking findings from both research projects was that many of the problems faced by adults with CP could be ascribed to a lack of support during their transition from childhood into adolescence and adulthood. It was clear that the facilities available while at school were often outstanding, but the care thereafter was insufficient and they literally felt 'lost'. Parents or caregivers from all socio-economic backgrounds, as well as healthcare

providers, struggled with this issue, since they didn't know where to seek care once the child outgrew the paediatric environment. It is quite clear from this experience that there is an immense gap between care for children and that for adolescents and adults with CP in our community.

Now that the medical community is able to improve the life expectancy of children with CP, we also have to take the responsibility for ensuring quality of care for these children who become adolescents and adults with CP.<sup>[8]</sup> It is important that we understand the secondary abnormalities as a result of the brain injury, and that we are able to combine the best interventions possible to aim for optimal quality of life.<sup>[8]</sup>

Largely because CP is seen as 'paediatric' rather than a life-long condition, adults with CP make much less use of healthcare and other services than children and adolescents.<sup>[9]</sup> It is important to realise what the impact of childhood interventions will be in adulthood; we should not only focus on CP, but also on the co-morbidities such as pain, chronic fatigue and deterioration in mobility and function or other neuromuscular and musculoskeletal challenges.<sup>[8-10]</sup> Prevention with early detection and treatment in a child and young adult will yield long-term dividends.<sup>[11]</sup>

It must also be emphasised that it is not only medical care that is lacking, but attention must also be paid to the psychosocial factors which have a major impact on the lives of people with CP.<sup>[12]</sup> Participation in, for example, employment, housing and relationships has a real impact on global quality of life in CP.<sup>[9,10]</sup> Sometimes facilities are available but adolescents, weary of the ongoing treatment they have received through childhood, elect to reduce their contact with the medical establishment, and this needs to be understood. Often the primary care practitioner is well placed to recognise these issues and respond accordingly.

Quite clearly this has to be approached holistically and in recent years a number of transition programmes have been established in developed countries. Although there is agreement about the need for

centres with lifespan care, there is quite a variety in emphasis between the centres, and further research is needed to evaluate best practice.<sup>[13]</sup>

Although there are major socio-economic and cultural differences between the developed world and our country, in conversation with South Africans with CP it is clear that all young people with CP face similar challenges during their transition through adolescence and into adulthood. There is no question that youngsters with CP in South Africa would benefit from support during this vulnerable period, irrespective of their background. This need for greater attention to transition applies not only to people with CP, but also other chronic childhood-onset conditions such as spina bifida,<sup>[10]</sup> autism or diabetes.<sup>[13]</sup> Furthermore, these issues also need to be framed in an African context, developing concepts and strategies that will be applicable elsewhere on our continent.

In conclusion, it is apparent that secondary biomedical and socio-economic consequences occur with age in many people with childhood-onset medical conditions. Many of those with CP have the potential to lead a fulfilling life and it is now recognised worldwide that appropriate support during the transition from childhood through adolescence and into adulthood greatly enhances their chances of doing so. The primary care practitioner plays a vitally important role in this and we also need to develop programmes that will offer the appropriate level of support.

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