TRANSITION TO ADULTHOOD: ENHANCING HEALTH AND QUALITY OF LIFE FOR EMERGING ADULTS WITH NEUROLOGICAL AND DEVELOPMENTAL CONDITIONS

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Overview
Most children with neurological and developmental conditions survive to adulthood. In their journey towards adulthood people with neurological conditions experience many transitions in various life domains. Leaving the family-centred environment of paediatric care for the individual-centred environment of adult services is a difficult challenge for these young people and their families. Poor transition from paediatric to adult health care has been shown to have a negative impact in these conditions with respect to adherence to medical care, health outcomes, and quality of life. This chapter provides the reader with insights into the processes of clinical transition of adolescents with neurological and developmental impairments, as well as with ‘points of entry’ to improve adult-oriented care using outcomes such as health and quality of life. Future models of care for this specific population are discussed.

Case scenario
I am 47 years old with cerebral palsy. I lead a fairly normal life, married with two children. I work as a manager. As a child 47 years ago, there was very limited information on cerebral palsy. It was something that was diagnosed and then you lived with it the best you could. I am very fortunate to have a mild version of the condition and also to have a loving environment to grow in and flourish in. One thing that I learned from a young age is that cerebral palsy was a stable condition that did not worsen. As I get older I find this to be different. I find my muscles and body in general to be achy and I lack energy (fatigue). When I saw a doctor (I do not have a family doctor) he attributes this to living with cerebral palsy and the impact of years of cerebral palsy on my body.
The help I am seeking from you is if you would know of any information about adults and ageing with cerebral palsy, what kind of doctor would be best suited for adults with cerebral palsy and what kind of specialist can help me find tools to help my everyday life? I need to have a complete evaluation, information to cope with my premature ageing process and to know what to do to help my condition. I feel alone because I have contacted a few doctors and I have not received much information.

Introduction
Most children with neurological and developmental conditions survive to adulthood. For example, with improved neonatal and paediatric care over the last few decades, life expectancy has changed dramatically for children with cerebral palsy (CP) (Strauss et al 2008, Baird et al 2011). In a report from Sweden, Westbom et al (2011) studied survival in a population of children with CP between 1990 and 2010. In that study virtually all children with good motor abilities, and 96% of the whole population of children with CP, survived into adulthood. Although the risk of death is the highest in fragile children with CP, their estimated survival is 60% at 19 years of age (Westbom et al 2011). The issue of growing up with CP has become a new reality, as it is for children and young people with many other neurological and developmental conditions such as spina bifida (Webb 2010, Oakeshott et al 2011), muscular dystrophy (Gordon et al 2011), and childhood onset epilepsy (Forsgren et al 2005).

In adolescence (derived from the Latin word *adolscere*, which means ‘growing up’) children transition from one state (childhood) to another (early adulthood). In late adolescence, young people usually, but not always, are able to regulate their own lives (demonstrating autonomy and independence). The term ‘emerging adulthood’ (Arnett 2004) has been suggested to describe a new stage in the life-course of an individual, one that is typically marked by high school graduation. Many young people in their late teens and early twenties feel that they are neither teenagers nor adults. Adolescence and emerging adulthood is a transition time when adult behaviours become established, and therefore it represents a window of opportunity to promote healthy behaviour.

Our view on transition should not, however, be too narrow. The literature on the unique needs and experiences of young people with neurological and developmental conditions has taught us that health should be broadly conceptualized and include physical, social, cognitive, and emotional aspects, with ‘participation’ (i.e. involvement in a life situation) as one of the ultimate measures of outcome (World Health Organization 2001). International health experts argued in a 2011 discussion paper for a more dynamic and empowering definition of health: ‘health is the ability to adapt and to self manage’ (Huber et al 2011). In other words, health of people with neurological and developmental conditions can be seen as a dynamic balance between opportunities and limitations, shifting through life. This balance is affected by external conditions, and the dynamics are most important at transition points, when a young person is dealing with significant changes in personal and environmental changes (Gorter et al 2011). The World Health Organization’s International Classification of Functioning, Disability and Health (ICF) (Fig. 22.1) provides both a detailed classification of aspects of people’s health...
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and function and a pictorial framework that presents the opportunity to consider health issues within a broader social–ecological context. The interconnectedness of the different boxes with aspects of health and contextual factors show that this is a ‘dynamic system’: changes in any area of the framework may potentially have influences elsewhere in the system (see also Chapters 2 and 4).

Transition in various life domains
For transition planning it is important to understand a young person’s functioning by examining the interactions among health condition, environmental factors, and personal characteristics and preferences (Kraus de Camargo 2011). Functional profiles based on the ICF, rather than on the medical diagnosis alone, can be useful in designing transition planning by addressing activities that young people consider important in their daily living. Major life events take place during the process of transition to adulthood, such as finishing education and starting a job, finding a partner, leaving home, and living on one’s own. Young adults, whether disabled or not, have to learn a range of new skills to enable them to regulate their own lives. This is a complex process that extends over several years. Transition to adulthood takes place in several domains of participation, including the use of healthcare services. A person’s transition does not necessarily follow the same pace in each domain of participation. For example, young adults can have paid work, but still live with their parents. Of a sample of young Dutch adults, between 16 and 22 years of age, with CP but without severe intellectual impairments, almost all were in the transition process or had reached autonomy for specific domains of participation (Donkervoort et al 2009). They organized transportation independently (driving a car, calling a taxi, or using public transportation: 90%), and went out to parties or for nightlife entertainment (80%). About 25% of the young adults with CP lived on their own, and 25% had a job, which is less than the general population of the same age. Over the previous 2 years they had become more independent in all areas, including finances, intimate relationships, and utilization of adult rehabilitation care (Donkervoort et al 2009). In a qualitative study, adults aged 18 to 35 with epilepsy and cognitive impairments spoke

Fig. 22.1 The International Classification of Functioning, Disability and Health framework (World Health Organization 2001).
clearly of the consequences of epilepsy in terms of education, employment, social life, self-esteem, and hope for the future (Gauffin et al 2011). In young people with neurological and developmental conditions, severity of impairment predicted whether they were employed or enrolled in postsecondary education, which in turn predicted greater participation in leisure activities and greater social interaction. Social interaction, in turn, was identified as a predictor of quality of life (MacCulloch 2012).

Healthcare transition

Although little is known about how young people ‘travel’ through healthcare services in their adolescence, there are key concerns regarding the ‘journey to adult life’ in young people with neurological and developmental conditions. Leaving the family-centred environment of pediatric care for the individual-centred environment of adult services (a major component of the medical transition or transfer) is a difficult challenge for young people with neurological and developmental conditions. Indeed, young people in many countries – and their parents/caregivers – have compared their transition experience to ‘falling off a cliff’. Poor healthcare transition has been shown to have a negative impact in all chronic conditions with respect to adherence to medical care, health outcomes, and quality of life. For example, 20- to 22-year-olds with CP are twice as likely to rate their health as poor compared with 15- to 16-year-olds (21% vs 9%) (Young et al 2010). In Canada, young people with CP visit physicians on an outpatient basis about twice as often as their age-matched peers. Moreover, annual hospital admission rates for young people and young adults were 11 and 4 times higher, respectively, than those of age-matched peers. Recent surveys in North America, Europe, and Southern Asia showed similar patterns of health care utilization when children with neurological and developmental conditions grow up and become (young) adults (Gorter 2009a).

Not surprisingly, there is a call for comprehensive care models in health care, with a life-course approach filling the gaps in medical and psychosocial care for young people and adults with chronic childhood-onset conditions, including transitional care programmes to promote a planned transition rather than a ‘laissez faire’ approach (Verhoof et al 2011, Oskoui et al 2012). The reality is that as a consequence of their conditions young people with neurological and developmental impairments are involved in many more ‘systems’. For example, healthcare and social services are very different in terms of their expectations of young people and families, and the transition can be highly stressful and requires a great deal of planning and preparation (Gorter 2009b, Young et al 2009, van Staa et al 2011). The transition process within the healthcare system alone is more complex than a simple transfer of care from a pediatric to an adult setting (Kraus de Camargo 2011).

This chapter discusses this subject with a focus on the key factors that must be considered to support the transition of adolescents with neurological and developmental conditions and their families, mainly in the context of health care. Capacity-building in young people, particularly fostering self-determination, problem-solving skills, and relationship building, has been identified as a strategy to empower young people with neurological and developmental conditions (Gorter et al 2011).

The basics of planned transition are simple and are common to all neurological and developmental conditions. The following themes will be addressed in this chapter:
1 Young people and their families need to be prepared well in advance for moving from pediatric to adult services, and they need to have the necessary skill set to thrive there.

2 Healthcare providers have to listen to young people’s views about their lives and their needs.

3 It is important to prepare and nurture adult services to receive young people with childhood-onset impairments, with whom those services are often not familiar.

**Theme I: Preparation of young people and their families**

The transition to adulthood is considered to be a critical journey within an individual’s life-course. Staying with the journey analogy, three key phases of the transition process can be distinguished: the preparation; the journey itself; and the landing in the adult world (Stewart et al 2009a). Preparation is critical to every journey. There is convincing evidence that the process of transition should start early with a life-course approach to development and transition, recognizing the chronic nature of childhood illness and impairment (Priestly 2001). While transitional concerns appear to intensify at the age of 17 prior to the transfer of care, children as young as 12 appear to contemplate transition (Moola and Norman 2011). This chapter focuses on the phase that takes place during a young person’s late childhood and adolescence as he or she begins to look ahead and prepare for adult life. The process of clinical transition should follow the stages of adolescence, and the preparation should begin when the adolescent is no older than 14 years of age.

Listening to the voices of young people and adults with CP, spina bifida, and acquired brain injuries of childhood in the province of Ontario, Canada, it becomes clear that young people and their families want to be prepared well in advance for moving from pediatric to adult services (Young et al 2009). Young and colleagues (2009) identified early provision of detailed information and extensive support as two possible solutions. For example, adolescents should have the opportunity to meet the pediatric healthcare provider on their own, so that they can practise and learn how to deal with the individualized adult healthcare system. At the same time, the parents can learn to ‘let their child go’. Rather than giving extensive support, a strategy to empower young people should be the focus of (pediatric) healthcare providers throughout the transition process. This strategy can be based on the shared management model, a planned systematic approach to a gradual shift in responsibilities from the healthcare provider and parents to the young person, as developmentally appropriate. This approach builds upon a life skills-building programme in which children are encouraged to take responsibility for tasks or household chores from a young age, and parents are required to be active in their parenting style (see Fig. 22.2) (Gall et al 2006). For this model to be effective, however, there will need to be clearly formulated descriptions of the tasks in healthcare transition, and evidence that this model contributes to children’s ability to adapt and to self-manage their life. Of course parents can (and, we believe, should) be encouraged to adopt and practise these basic concepts from early in their children’s life and to continue their role based on the needs and abilities of the young person. Therefore, parents require ongoing and coordinated support to navigate the complex process of service transition, and an approach fostering family involvement will strengthen them in their roles as care provider, manager, supervisor, and consultant, for example through parent-to-parent support.
So far, there are few data evaluating the effectiveness of interventions to improve the preparation of young people for health care transition (Liptak 2008, Grant and Pan 2011). In an outcomes-oriented preparation process one would hope that the young people would have the ability to summarize the main (medical) issues of their condition, for example in the so-called 3-minute summary, at the time that their care is transferred to adult healthcare providers. Another approach to promote partnerships between young adults and service providers is the use of the Youth KIT (Keeping It Together, Youth Version; Stewart et al 2006), a tool developed by researchers at the CanChild Centre for Childhood Disability Research at McMaster University, Hamilton, ON, Canada, that recognizes adolescents/young adults as experts on their own needs (Stewart et al 2009b). The Youth KIT promotes information gathering and health self-management and is validated in the paediatric setting and during transition. This tool is being tested in a project together with an Internet-based Transition Coordinator (TRACE) with which young people can interact online (Punthakee and Gorter 2011). The novelty of this approach lies within the way one delivers services to young people and young adults, because it shifts the paradigm from ‘doctor knows best’ towards an empowered young person who enters the adult world knowing what is important and how to deal with the system.

It is hoped that this presentation of processes and information will promote a new paradigm of patient-driven transition navigation that will enhance self-determination and continuity of care. For young people with neurological and developmental conditions and service providers the Rotterdam Transition Profile can be used to focus attention on developing autonomy in several domains of participation (Donkervoort et al 2009). The profile monitors a young person’s transition process in seven areas of life and healthcare management, distinguishing between transition phases that progress from no experience, dependency on adults, the in-between phase (experimenting and orientating to the future), to self-reliance or autonomy. For young people with neurological and developmental conditions the Rotterdam Transition Profile can be introduced early on at age 14. The profile items allow young people...
to reflect on their development and to talk about mobility (transport), school, employment, finances, relationships and sexual experiences, living situation, and leisure activities. Both an interview version for use in young person–clinician communication and a self-report version for young people are available in English, Dutch, and Norwegian (Rotterdam Transition Profile, 2010) (Table 22.1).

**Theme II: Listen to young people’s views**
Health and quality of life in individuals with neurological and developmental conditions can be enhanced by giving young people a voice. When adolescents were asked to describe their experiences with health care they all greatly appreciated the opportunity to express their opinion (Siebes et al 2007, Gan et al 2008). An inventory among adults with CP revealed a broad spectrum of unmet needs. The most often-mentioned need was for information on their condition (80%), referring to consequences, complications, and causes of CP. This need for information might be due to an inadequate transfer of information to the child as he or she is growing up, or to new questions arising when a child reaches adulthood (Nieuwenhuijsen et al 2008). In a study using the client-centred perspective, young adults with CP, and especially those with lower levels of gross motor functioning, indicated several problems in daily life (Nieuwenhuijsen et al 2009). They identified problems in mobility (using public transport, driving a car), work (seeking employment), preparing meals, housework (e.g. cleaning), and active recreation activities (e.g. sports). Several problems referred to activities that are considered age appropriate and may appear when a child with CP grows older. Therapists and physicians should be aware that new types of problems may arise when a young person with CP reaches adulthood, and these may warrant other approaches or interventions than those that were appropriate in paediatric care (Nieuwenhuijsen et al 2009).

Lessons learned from the experiences and perceptions of older adolescents with CP were that service providers should be encouraged to involve young people actively in making choices on mobility methods, task accommodations, assistive technology, and environmental modifications, rather than therapy with a focus mainly on impairments and activity limitations (Palisano et al 2009). The complexity of the choices and trade-offs made by young people with neurological and developmental conditions supports the importance of considering the dynamic interaction of person and environment, as part of the developmental journey facing all young people, and the need for discussing the trade-offs inherent in the choices that they are making now and for the future. One of the important choices that young people with CP identified was about the amount and type of support they need in order to participate in social activities (Stewart et al 2012). In general, the recommendation for any service provider is to ask clients about the meaning of various experiences in their life, including mobility, health, and their quality of life – all of which should place the focus more on choices and solutions, rather than solely on their problems.

**Theme III: Prepare and nurture adult services (see also Chapter 23)**
It is clear that individuals with neurological and developmental conditions require ongoing services to decrease morbidity and improve quality of life (Aisen et al 2011, Webb 2010). Adequate routine medical, dental, and specialized care should be provided to all individuals living with neurological and developmental conditions (Liptak 2008, Webb 2010). While in
### Table 22.1
Rotterdam Transition Profile (Donkervoort et al 2009)

<table>
<thead>
<tr>
<th>Participation domains</th>
<th>Transition phases</th>
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<th>1</th>
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<tbody>
<tr>
<td>Education and employment</td>
<td>0. Following no education, no job</td>
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<td></td>
<td>1. General education</td>
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<td>2. Vocational training, work placement</td>
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<td>3. Paid job, volunteer work</td>
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<td>Finances</td>
<td>0. No pocket money</td>
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<td></td>
<td>1. Pocket money, clothing allowance</td>
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<td></td>
<td>2. Job on the side, student grant</td>
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<td>3. Economically independent: job income, benefits</td>
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<td>Housing</td>
<td>1. Living with parents, not responsible for household activities</td>
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<td></td>
<td>2. Partly responsible for household activities, domestic training, or seeking housing</td>
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<td>3. Living independently</td>
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<td>Leisure (social activities)</td>
<td>1. Young adult arranges leisure activities with peers at home</td>
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<td></td>
<td>2. Young adult arranges leisure activities with peers outside the home, during daytime hours</td>
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<td></td>
<td>3. Young adult goes out in the evening with peers</td>
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<td>Intimate relationships</td>
<td>0. Young adult has no experience with dating</td>
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<tr>
<td></td>
<td>1. Young adult has experience with dating but not yet with courtship</td>
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<td>2. Young adult has experience with courtship</td>
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<td>3. Young adult has a current romantic relationship/a partner</td>
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<td>Sexuality</td>
<td>0. Young adult has no experience with French kissing</td>
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<tr>
<td></td>
<td>1. Young adult has experience with French kissing</td>
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<td></td>
<td>2. Young adult has experience with caressing under clothes, cuddling nude</td>
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<td></td>
<td>3. Young adult has experience with sexual intercourse</td>
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<td>Transport</td>
<td>1. Parents or caregivers transport the adolescent/young adult</td>
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<td>2. Parents or caregivers arrange transport, but they do not go with him or her</td>
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<td>3. Young adult arranges transportation him-/herself</td>
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<td>Health care</td>
<td>1. Parents formulate care demands</td>
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<td>2. Parents and young adults formulate demands together</td>
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<td>3. Young adult formulates care demands him-/herself</td>
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<tr>
<td>Care demands</td>
<td>1. Parents apply for services and aids</td>
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<td>Services and aids</td>
<td>2. Young adult learns the procedures to apply for services and aids</td>
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<td>3. Young adult applies for services and aids him-/herself</td>
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<td>Rehabilitation services</td>
<td>In the past year:</td>
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<td>1. Young adult consulted paediatric rehabilitation care</td>
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<td>2. No consultation of paediatric rehabilitation care</td>
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<td>3. Young adult consulted adult rehabilitation services</td>
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Rotterdam Transition Profile, © Department of Rehabilitation Medicine, Erasmus MC – University Medical Centre, Rotterdam: www.erasmusmc.nl/revalidatie/research/transition/
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temporal healthcare providers and policy makers hardly disagree on this human right, in reality young people and adults with CP, spina bifida, and acquired brain injuries of childhood onset identified challenges in transition, including: lack of access to health care; professionals’ lack of knowledge; and lack of information and uncertainty regarding the transition process (Young et al. 2009). Because most neurological and developmental impairments have traditionally been viewed as disorders of childhood, adult services are not trained to accommodate the needs of these individuals. For example, adult healthcare providers were not taught about management of adults with childhood-onset conditions in their residency training (Aisen et al. 2011). Appropriate training (knowledge, attitudes) for medical and dental trainees can help to build capacity at large. Resource centres with transition tools and tips should be established for people with neurological and developmental conditions, including the transition of young people to the adult healthcare system, as well as for their families, their healthcare team, and other service providers. See, for example, http://healthytransitionsny.org and http://www.gotttransition.org/. Making the links is essential for overcoming the gap between paediatric and adult specialists and primary healthcare providers (Gorter 2012). At an individual or programme level there is a need to create a network of adult healthcare providers, built around the individual with a neurological or developmental condition and his or her family. Collaboration is also needed at an organizational level to provide healthcare providers with support and resources throughout the individual’s lifespan.

For example, a Dutch network of rehabilitation centres (TransitionNet) offers innovative transition and lifespan care for young persons with childhood-onset impairments and disabilities (16–25 years). In young adult teams (YATs), they develop and implement age-appropriate interventions aiming to improve the young people’s autonomy in several life areas (Roebroeck et al. 2009). YATs typically include a consultant in rehabilitation medicine, a psychologist, therapists, and a social worker. Both health problems and necessary life skills, as indicated above, will determine the goals negotiated with the young person (Chamberlain and Kent 2005). In the UK, YATS have been shown to be cost effective (Bent et al. 2002). Building on participation domains of the Rotterdam Transition Profile, the Dutch centres developed a series of eight interventions for young people, focusing on different topics and life areas, including healthy lifestyle and physical fitness. A module for parents is available to encourage them to give their child the room to experience new situations and develop towards independence and autonomy. Studies of the feasibility of some of these interventions suggested preliminary positive findings, with the majority of participants achieving intervention-specific goals, such as increased levels of occupational performance and participation in paid work (work intervention), sexual self-esteem (intimate relationships), everyday physical activity (healthy lifestyle), and a stronger focus of families and professionals on the child’s development of autonomy in life areas (skills for growing up) (Buffart et al. 2010, Hilberink et al. 2012, Verhoef et al. 2012). In addition to providing developmentally appropriate transition care, YATs create the opportunity for medical checks and adequate follow-up at adult age, if needed.

Conclusion
The developmental trajectories of young people with neurological or developmental conditions can go in many directions, depending on the interaction of personal risk and protective
factors with environmental barriers and supports. These interactions are most important at transition points, when a young person is dealing with significant challenges with personal and environmental changes, including the transition from paediatric healthcare to adult healthcare providers. It is through positive, developmentally appropriate life experiences throughout their childhood and adolescence, and regular opportunities for participation and inclusion, that young people with neurological and developmental conditions can prepare for a healthy, successful, and meaningful adult life.

REFERENCES

*Key references


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