To gain new knowledge regarding optimising physical function in adults ageing with cerebral palsy

Dr Prue Morgan
2016 Churchill Fellow

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Signed PRUE MORGAN Dated 27/06/17
Keywords

- Cerebral palsy
- Rehabilitation
- Disability
- Physical activity
- Mobility
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Acknowledgements

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The report was assembled following visits to the following institutions. If necessary, information was clarified or supplemented via the facility’s web pages on the internet, or additional resources provided by my hosts following the visit such as relevant publications. Any errors are mine alone.
Executive summary

‘To gain new knowledge regarding optimising physical function in adults ageing with cerebral palsy’
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Adults with cerebral palsy (CP) are a significant community in Australia who experience unique health challenges as they age, attributed to their developmental disability, resulting in abnormal neurological and musculoskeletal systems. Although Australia is a world leader in paediatric care for CP, their adult counterparts have experienced challenges in accessing quality health services targeted to their needs. This fellowship aimed to gain new knowledge about how to optimise physical function in adults with CP, as a standalone program, or embedded in a life skills program.

Highlights

There were so many learning opportunities that I engaged in throughout the four weeks of my fellowship. Some highlights were:

- The opportunity to meet with and speak to international clinical and research leaders providing health care for adults with CP, whose publications I had previously read and who have influenced my current interest, research and practice in the field
- Observing clinics from across the world developed using best practice that optimise the development of health efficacy in adolescents and young adults with CP
- Learning about current research that aims to enhance physical capacity and reduce adverse health outcomes in adults with CP
- Establishing ongoing international research and clinical collaborations in the field of falls, mobility and physical function in adults with CP

Lessons learned and conclusions

I have learned much regarding the needs and wants of adults with CP across the world with respect to optimising their health outcomes, and more specifically, their physical function. The following are particular issues that resonated with me:

- That transition programs for young people with CP should commence early (in early teens) within a dedicated clinic, rather than as an ‘add on’
- That clearly articulated pathways for those with CP exiting paediatric health care and entering adult services are required, with acknowledgement of the extra time and care required for complex disability
- That ambulant adults with CP may have the capacity to reduce their falls risk and improve their balance through targeted training programs, ideally delivered in a community setting
- That adults with CP have a high risk of adverse health outcomes through multi morbidity – adult health care providers need to focus on minimisation of these risks
- That primary health care providers need to be aware of the specific health issues and needs of adults with CP through close relationships with ‘expert’ providers
I will aim to disseminate my findings through

- University undergraduate and post graduate health professional curriculum renewal
- As physical activity programs may be funded through the NDIS as 'participation' goals, I will provide student fieldwork experience with NDIS health providers to build workforce capacity in the disability sector
- Providing professional development for my university academic colleagues, Australian Physiotherapy Association and Australian College of Physiotherapists members, and increasing awareness of the topic through publications (such as ‘In Motion’, APA’s national magazine)
- Presentations at national and international conferences targeted at health professionals
- Liaison with local disability service providers to assist in developing and delivering evidence based programs, and making information accessible to those with CP
- Advocacy through local, state based and national health and government networks for improved services for this population
- Participation in local and international research collaborations investigating aspects of health interventions to optimise physical function and health outcomes in adults ageing with CP
Week 1: Ontario, Canada

The Ron Joyce Children’s Health Centre, McMaster Children’s Hospital, Hamilton, Ontario

Dr Jan Willem Gorter, MD, PhD, is a Professor and physiatrist (rehabilitation specialist) with a particular focus on transition services for young people with developmental disabilities. He currently leads the Stay-FIT program which studies the effects of a physical activity and active lifestyle intervention for youth with cerebral palsy. He also co-leads the transition study (TRACE) which facilitates youth with chronic health conditions in their transition from paediatrics to the adulthood health care system.

Holland Bloorview Kids Rehabilitation Hospital, Toronto, Ontario

Dr Gillian King, holds a Canada Research Chair in Optimal Care for Children with Disabilities. Her primary interest is in the psychosocial aspects of paediatric services and child, youth, and parent well-being. Her research focus includes participation of children with disabilities, youth transitions, parent wellness and resilience, and client engagement.

Hutton House, London, Ontario

Hutton House is a community based facility offering day programs for those with significant developmental disability such as cerebral palsy. Jeanette Dutot is the Executive Director of Hutton House.
Week 2: North Carolina, United States of America

**Center for Human Movement Science, University of North Carolina, Chapel Hill**

Dr Deborah Thorpe is a leader in national and international research consortiums investigating aging and developing interventions to improve function in individuals with cerebral palsy. Her clinical practice focuses primarily on neurological rehabilitation in individuals with developmental disabilities. Many of her patients have age-related changes in gait and balance abilities secondary to neurological disorders. Dr Thorpe’s own research focuses on improving fitness and wellness across the lifespan in individuals with developmental disabilities.

Week 3: Amsterdam, The Netherlands

**29th European Academy of Childhood Disabilities conference, Amsterdam, The Netherlands**

**Pre conference Symposia: Transition to Adulthood – current knowledge and future research**

Organizing Committee: Marij Roebrock, The Netherlands; Allan Colver and Helen McConachie, UK; Prof Wilma van der Slot, The Netherlands; Prof Jan Willem Gorter, Canada

Contributors: A young adult with Cerebral Palsy, The Netherlands; Dr Chistina Akre, Switzerland; Dr Philip Moons, Belgium, and Elisabet Rodby Bousquet, Sweden

Week 4: Oslo, Norway and Gothenburg, Sweden

**Sunnaas Rehabilitation Hospital, Oslo, Norway**

Prof Reidun Jahnsen is a physiotherapist and researcher. She oversees the CPOP database. CPOP is a systematic motor follow up program for children/adolescents with cerebral palsy (CP) in Norway, based on a model from the CP follow-up program (CPUP) in Sweden.

Dr Grethe Maanum is a rehabilitation physician who leads the program for adults with complex disability (such as cerebral palsy) at Sunnaas Rehabilitation Hospital in Oslo.

**Habilitation and Health, Gothenburg, Vastra Gotalandsregionen, Sweden**

Dr Arve Opheim is a physiotherapist and researcher with appointments at Sunnaas Rehabilitation Hospital, Norway and University of Gothenburg, Rehabilitation Medicine, Sweden. He is the Director of Research at Habilitering & Hälsa (Habilitation and Health), Västra Götalandsregionen.
Presentations delivered

May 2, 2017

‘Falls and mobility dysfunction in ambulant adults with cerebral palsy – an Australian perspective’
Presentation to clinicians and researchers, Holland Bloorview Kids Rehab, Toronto, Ontario

May 9, 2017

‘Falls and balance dysfunction in adults with cerebral palsy - preventable or inevitable?’
Presentation to faculty, Division of Physical Therapy, UNC, Chapel Hill, North Carolina

May 19, 2017

‘Gait characteristics, balance performance and falls in ambulant adults with cerebral palsy’
Platform presentation at 29th European Academy of Childhood Disabilities conference, Amsterdam

May 22, 2017

‘Research directions in cerebral palsy and acquired neurological conditions across the lifespan’
Presentation to administrators, clinicians and researchers, Sunnaas Rehabilitation Hospital, Oslo

May 23, 2017

‘Update from Australia: Adults ageing with cerebral palsy – what do we know?’
Presentation to clinicians and researchers, Habilitation and Health, Gothenburg

Filipa Moita de Deus, Physiotherapist from Portugal, with Prue Morgan at EACD conference in Amsterdam
Introduction

Cerebral palsy (CP) is the most common physical disorder of childhood, is associated with lifelong disability and affects around 40,000 people in Australia. Traditionally regarded as a childhood condition, it is now better recognised as a lifespan disorder, with adults living with CP outnumbering children 3:1 in countries such as Australia (1). The contemporary definition of CP defines it as a group of developmental conditions of varying severity, rather than as a single disease or disorder. Attributed to a lesion in the immature brain either before or shortly after birth, motor disorders of CP are often accompanied by disturbances of sensation, perception, cognition, communication, behaviour, epilepsy, and secondary musculoskeletal problems.

Australia is regarded as an international leader in the provision of quality healthcare for children with CP. Most commonly coordinated through a tertiary centre, children with CP access a range of services including intensive intervention programs for pre-schoolers, ongoing therapy throughout school years, orthopaedic surgery and spasticity management tailored to gross motor function, coordinated by a team of experts in the paediatric setting.

However, there has been growing disquiet regarding the limitations in health and wellbeing services available to this population after they exit paediatric care. Instead of a seamless transition to the equivalent suite of adult services, adults with CP may struggle to identify and engage with appropriate health services, or may be offered inappropriate services to meet their complex disability needs (2). Many adults with CP experience complex motor symptoms. Progressive lower limb problems occur during growth due to abnormal neuromuscular function, leading to contractures, over-lengthening of muscles, abnormalities within growing bones and joint damage such as hip dislocation. They may experience problems with pain, fatigue, mobility decline, increasing balance dysfunction and falls (3-5). Given this complexity, understandably many health professionals report that they lack sufficient skills and knowledge to provide services to this population (2). Whereas there are established and evidence-informed programs to assist adults aging without developmental disability, such as geriatric Falls and Balance programs, these offerings do not suit the needs of a 35 year old with CP who is also experiencing balance decline and falls. Not only do these programs targeted at the older adult not suit a younger person with an abnormal neuromuscular system, they are considered socially unacceptable.

We now know that optimising physical activity is an essential part of every person’s wellness. Guidelines regarding minimum physical activity amounts have been published by the Australian Government Department of Health, encouraging physical activity on most days of the week. But how do we encourage and assist an adult with a lifelong physical disability to be physically active?

There are a range of challenges experienced by an adult with CP attempting to maintain a healthy lifestyle and source appropriate health services:

- Health promotion and physical activity programs may not exist or may not be suitable for the adult with CP
- The most effective components of any physical activity intervention offered to this population are not well known
- Health professionals may lack knowledge and skills in working with this population (traditionally considered a ‘paediatric’ disorder)
Adults with CP may not have had the opportunity to develop the skills and knowledge in the transition from paediatric care to empower them to advocate for their own health needs.

Finally, it is recognised that CP is not a homogenous condition. No two people with CP will have identical problems. It is unlikely that one ‘solution’ will suit everyone with CP. Rather, the aims of this report are to explore options and offer potential solutions for consideration.
Fellowship aims

The aim of this fellowship was to observe programs that promote physical function in adults ageing with CP either as stand-alone activities, or embedded within an overall ‘life skills’ program promoting physical health and wellbeing in this population. Given the emphasis on evidence-based practice within Australia, it will also be relevant to identify effective components of any intervention offered, if possible, through exploring relevant research into this topic.

It is important to acknowledge that an adult with CP doesn’t suddenly acquire a disability as an adult, but has lived their whole life with their condition. As there is increasing recognition of the ‘lifelong’ need for physical activity in those with CP, programs that commenced in late adolescence to prepare an individual to ‘transition’ across into adulthood health services through the development of self-health knowledge and self-efficacy were also included as an important aspect of the fellowship.
Week 1

Ron Joyce Children’s Health Centre, Hamilton, Ontario

My host was Dr Jan Willem Gorter, MD, PhD, a Professor and physiatrist (rehabilitation specialist) who has particular interest in transition services for young people with developmental disabilities such as CP, and optimising physical activity in this population.

Background information

In the Hamilton region, health records are readily accessible by Hamilton Health Sciences staff involved in the healthcare of an individual via electronic access of clinic visit reports, radiography and laboratory results. This means that there is access to paediatric records from those who take over the care of that individual as an adult, with no risk of ‘losing’ information, or being unable to access pertinent health information. This is supplemented by a 2 page summary of key current and active health problems prepared by the paediatric health care team for the adult providers during the final transition period.

An ‘alert’ is identified on the electronic medical record to flag the need for additional support relating to complex care needs. This is particularly valuable for young adults with complex disability requiring emergency care/inpatient admission in the adult health system as it informs health care providers of this need. A ward with up to 6 beds available for family-centred care for young adults with developmental disability (similar to the model of inpatient care at a paediatric inpatient facility) is accessible for this purpose. Dr Gorter is now proactively consulted by Adult health service administration regarding the care of young adults with complex disability within adult health services.

For those with developmental disabilities, by law they cannot access medical care in the paediatric services after the age of 18 years. However they can access paediatric therapy services up to the age of 19 years, allowing a further 12 months to ensure that transition to adult services is established.

Teen transition clinic (TTC)

Adolescents with complex physical disabilities such as cerebral palsy (CP) are referred to the teen transition clinic from age 13 onwards. This clinic is a stand-alone clinic, not an ‘add on’ to an existing medical clinic such as a spasticity clinic or developmental paediatrics clinic. The clinic’s focus is exclusively on preparing the adolescent to ‘transition’ to adult health care services, able to describe their health condition, be independent in seeking and making appointments, and decisions regarding health care needs (6). An App (able to be downloaded on an iphone or similar) is currently under development – ‘My transition’ to facilitate this process. The TTC uses the Transition Q (7) and Rotterdam transition profile (8) to assist the process and provide concrete areas of discussion with
the young person with CP during the clinic appointment. The ‘Youth Kit’, a folder with ‘homework’ tasks is also used (frequently facilitated by the treating occupational therapist) to drive independence in responsibility for own health care. Downloaded pages from the CanChild website are inserted into this folder as the adolescent transitions over several TTC appointments. Evaluation of the TTC has demonstrated the need for a collaborative approach between the transitioning adolescent, parents and paediatric and adult health care providers for optimal efficacy (9). An important component of the TTC is the onsite availability of treating therapists to attend the clinic with the adolescent, and provide ongoing therapy outside of the clinic (note – only available for local Hamilton residents, not feasible for those accessing the TTC who come from rural centres). A further important component of the TTC is the geographical location adjacent to an adult health service to facilitate the linkage to ongoing care after the age of 18.

Y Fit 4 U

The Y Fit 4 U program gives adolescent patients of Mc Master Children’s Hospital’s (MCH) Children’s Developmental Rehabilitation Programme (CDRP) the opportunity to enhance their physical activity while supervised by CDRP physiotherapists, YMCA staff and volunteers. Their programs, based on their abilities and fitness goals, have been developed by the YMCA staff and MCH physiotherapists who assess the adolescents at the beginning of the 12-week program. The Y Fit 4 U program is part of a broader partnership between Hamilton Health Services, the YMCA and McMaster University, called ‘Live Well’. It is a community model of health care based on a chronic disease self-management framework. Participants are ‘buddied’ with a volunteer to assist and motivate them during the gym program. Many of the volunteers in the Y Fit 4 U program are university students.

After ‘graduating’ from the 12 week supervised program (available two nights a week), adolescents and young adults with disabilities such as CP are able and encouraged to continue to attend the gym at a reduced membership cost (i.e. not time limited). Although challenges have been experienced through the need to constantly upskill fitness centre staff in working with those with disabilities due to staff turnover, a key component of the success appears to be the onsite availability of a physiotherapist experienced in working with those with complex disability not to provide constant supervision, but to problem solve if any issues arise.

1 https://www.canchild.ca/system/tenon/assets/attachments/000/000/559/original/7YouthKITTN.pdf
Holland Bloorview Kids’ Rehabilitation Hospital, Toronto

Background information

Holland Bloorview Kids Rehabilitation Hospital is Canada’s largest children’s rehabilitation hospital which aims to improve the lives of children with developmental and acquired disabilities. It is located in East York, a suburb north of downtown Toronto. Most importantly (from my perspective) is its location physically adjacent to the adult rehabilitation facility – Toronto Rehab.

Of relevance, Holland Bloorview’s ‘no limits – campaign for childhood disability’ report to donors 2008-2016 identifies ‘transition to adulthood’ as a particular focus, a new emphasis to facilitate the journey to adulthood for adolescents with disabilities by developing new programs.

My hosts were Dr Gillian King, who holds a Canada Research Chair in Optimal Care for Children with Disabilities and has particular interest in youth transitions, and Jesiqua Rapley, the Research Coordinator for the Residential Immersive Life Skills (RILS) Study.

Overview of programs

There are a range of programs offered by Holland Bloorview that promote physical activity for adolescents with developmental disability such as CP throughout the transition to adulthood period. Some examples are:

- ‘Recreation, Respite and Lifeskills’ fair, where information regarding adapted equipment and recreation programs, leisure programs (such as aquatics), and camps is provided in a gymnasium environment.
- The Youth Weekend Retreat is designed to support independent experiences. It is for young adults with disabilities to come together for a weekend of specialized services including life skills strategies, recreation activities and social opportunities.
- Adapted recreation equipment loan service for clients and families to borrow for up to 2 weeks for no charge. This service encourages healthy and active participation for adolescents/young adults with disability. By using adapted recreation equipment, it provides the opportunity for adolescents and young adults to increase their engagement in meaningful recreation activities. It also provides an opportunity to try equipment before purchase.
Residential immersive life skills program (RILS) for youth with disabilities

This innovative program (RILS) aims to assist youth (up to age 21 years if still in high school) develop foundational life skills to assist successful transition into adulthood (10, 11). It focuses on developing skills in problem solving, critical thinking, decision making and resilience through experiential learning. Structured around an intensive daily program that facilitates life skill acquisition such as grocery shopping, public transport access, laundry, cooking and socialisation, it implicitly develops self-efficacy to allow young people with disabilities to gain confidence and competence in independent living skills. Although not explicitly targeted at enhancing physical activity, by its nature it encourages young people with disabilities to be active and pursue their own leisure and physical activity interests. Evaluation of this program has supported the development of youth empowerment through the provision of challenging experiential opportunities as well as changing health service provider views and parental attitudes (12).

RILS is one participant in a range of immersive life skills programs that are offered throughout Ontario by 3 major children’s treatment centres – Holland Bloorview Kids’ Rehabilitation Hospital, Erinoak Kids Centre for Treatment and Development, and McMaster Children’s Hospital (www.oipr.ca).

LIFEspan clinic

The LIFEspan clinic service is a joint initiative of Holland Bloorview and UHN-Toronto Rehab and promotes transition to adult services for adolescents with developmental disability such as cerebral palsy. The clinic commences at age 14 years and offers annual appointments until the young person
exits paediatric care (before their 19th birthday). It is staffed by a nurse practitioner, a social worker, a youth facilitator and a lifeskills coach².

After age 18, the young person will receive health services from the adult clinic at UHN-Toronto Rehab (adjacent building) providing a single point of access for consultative and coordinated rehabilitation services. Annually they can identify their ‘top 3’ health disciplines that they would like to see (from nurse practitioner, physiatrist, lifeskills coach, social worker, occupational therapist, speech therapist, physiotherapist). There is an opportunity to have an additional two sessions with a discipline outside of the clinic. If a client needs more intensive intervention, they are referred for block therapy to the local community resources.

Sport fit

This program is focused on the promotion of healthy eating and physical activity in a non-hospital environment. Partnering with a local YMCA the program aims to encourage adolescents/young adults to try new physical activity experiences in a community gymnasium environment tailored to their ability. Student volunteers participate as assistants (not necessarily university health students), at a comparable life stage. Note – the YMCA offers ‘free teen nights’ on Friday evenings.

Hutton House, London, Ontario

My host was Mrs Jeanette Dutot, the Executive Director of Hutton House.

Background

Hutton House was recommended to me to visit as an outstanding model of service delivery for adults with significant developmental disabilities. It is funded from a variety of sources including Ministry of Community and Social Services (project based and individualised funding), Ministry of Health (for the day respite program), and from their Foundation and donation scheme. A noticeable drive to increase funding via social enterprise is apparent, reported the Executive Director. Hutton House Association for Adults with Disabilities is a registered charity to provide services to adults with disabilities. Located across three sites in London, south Ontario, their mission is ‘to promote and support persons with disabilities through learning and life enhancing programs that focus on each individual’s strengths, abilities and interests’. Providing a wide range of services from learning skills, to employment preparation, to arts and music, for the purposes of the Fellowship I have focused on programs that target physical activity and/or include physical activity as a component of life skills preparation. Their typical participant has a significant physical and/or intellectual developmental disability, is aged between mid 20’s to mid 50’s living either in a group home, with family, or in supported independence.

² A life skills coach has qualifications as a therapeutic recreation specialist. One aspect of the therapeutic and life skills role is to facilitate engagement of the young person with physical activity programs as a tool to work towards other goals.
Fitness & Healthy Living

The stated goal of the Fitness & Healthy Living program is to ‘enhance quality of life through physical fitness, wellness and nutrition’. Staffed by personal trainers, a personalized exercise program is developed which may include wall stations with bands, a specialized MOTOmed, cardio training, Skierg, airdyne cycle and treadmill. Small group classes are also offered such as Wii Fitness, Circuit training with a Stretch, and Jazzercise Lite. An adapted Yoga program is also under development to cater for those with physical and/or intellectual disabilities.

Through an ongoing relationship with Special Olympics, sport specific training is also available for swimming, boxing, track and field, sledge (seated) hockey, and bowling. Independent access of the gymnasium and equipment is available for a low cost gym membership (around $15/month). Volunteers (some of whom are university students) are able to provide assistance if required by participants.

Note: the facility also offers Adaptive Fitness Specialist Certification (AFS) for support workers, fitness professionals, students, family members and/or volunteers who wish to develop skills to work in health and wellness with people with disability.

Other programs such as LIFEworks and Day Break are available catering for people with a range of severity of developmental disabilities which also include a physical activity element within the program tailored to the abilities of participants. Those with severe disability, such as those attending the Day Break program, also have massage services available.
Week 2

Center for Human Movement Science, University of North Carolina, Chapel Hill, USA

My host for this visit was A/Prof Deborah Thorpe, a physical therapist and researcher with particular interest in aging and interventions to improve fitness, wellness and function in adults with cerebral palsy.

Background information

In North Carolina, there are two major streams of funding for health care – Medicare and Medicaid. In my understanding, those over the age of 65, or deemed permanently disabled, are eligible for Medicare. In North Carolina, adults under the age of 65 with low socio economic status (SES) may be eligible for Medicaid (https://www.medicaid.gov/medicaid/eligibility/index.html). It is possible to receive funded health care via a complex combination of Medicare and Medicaid if you are an adult less than 65 years old with a permanent disability, such as CP and not employed. However, most pertinent to my fellowship, all physiotherapy (physical therapy) services in North Carolina are ‘billed’, even if provided within a public facility, and hence there is a documented record of claimed services.

Dr Thorpe provides physical therapy interventions for adults with CP through the Physical Medicine and Rehabilitation program, through community based services (including services to those living in assisted accommodation), and a community aquatic program. She has two relevant significant funded research projects underway – ‘testing novel measures of community function and participation in adults with CP’ and ‘towards transition and self-management: assessing the needs of individuals with CP in North Carolina’.

Claims database interrogation

As every health intervention must be logged for payment, in US there are significant databases that hold records of claims for various health interventions. Many adults with CP experience chronic pain as a result of altered biomechanics creating premature joint degenerative changes particularly in hips, knees and spine (5). Dr Thorpe is exploring comparative interventions offered to adults with CP to manage lower limb pain in comparison to age-matched normative sample. The evidence suggests that those with CP experience considerable pain limiting their ability to remain physically active, but access health services to a lesser extent than their non-disabled peers. Some orthopaedic surgeons may be reluctant to perform joint arthroplasty due to the additional complexity of their developmental disability and lack of familiarity with CP. However, when offered surgical remediation, outcomes are equivalent to their non-disabled peers (13, 14) with improvement in pain and function. Rates of chronic pain are probably equivalent in adults with CP living in Australia but requires further
investigation. Whether the access inequity exists in Australia is unknown. The equivalent claims data base does not exist in Australia.

Dr Thorpe is also involved in the development of a national patient-reported outcomes registry for adults with CP. The potential for the Australian CP database to include this information in the future will be explored (https://www.cpregister.com/).

Optimising balance and gait training for ambulant adults with CP

Many ambulant adults with CP experience gait and balance dysfunction which frequently escalates throughout their adult years – well before their non-disabled peers (15). Intervention research in adults with CP is limited and insufficient to guide evidence-based decision making regarding which deficits to target to prevent or remediate any mobility decline. We therefore know little about how to reverse this dysfunction, or even if improvement is possible to enhance physical activity in this population who have lived their whole lives with abnormal mobility. Dr Thorpe and her PhD student Ilana Levin are exploring elements of gait and balance dysfunction in adults with CP with a view to developing effective training models. Using three dimensional gait analysis to record kinematic and kinetic gait data, and a split belt treadmill to investigate asymmetry in the gait pattern, they are undertaking a series of research projects to guide future interventions.

Compared with their peers, gait of adults with CP may be slower, unstable, less mechanically efficient, with a higher energy cost, and asymmetrical in step length and/or stance time (16). Although many adults with CP demonstrate gait asymmetry, it is unknown as to if they can reduce gait asymmetry with training. The goals of Levin et al’s study (16) were to assess the feasibility and efficacy of a training program to reduce gait asymmetry using concurrent visual and proprioceptive feedback with overground gait training. All interventions were individualised, and followed principles of motor learning such as whole-task practice (e.g. walking at various speeds), part task practice (e.g. weight shifts and dynamic control exercises). Their case series demonstrated improvement in balance and reduction in gait asymmetry which may have contributed to positive gains in other outcomes such as gait speed, gait efficiency, and dynamic balance (16). Two participants also significantly reduced their risk of falling to sub-risk threshold. These participants also demonstrated the largest pre-training asymmetry and the largest reduction in asymmetry (16). These results suggest the potential for targeted interventions to remediate balance and gait dysfunction in some ambulant adults with CP.

Falls is an area of particular concern for adults with CP and the health professionals providing care, particularly for those who are ambulant, classified as Gross Motor Function Classification System I-III (Appendix 1). The UNC research team are interested in the capacity of an ambulant adult with CP to learn to improve their ability to respond to a trip or a slip. Using three dimensional gait analysis, and a program that intermittently simulates a trip or slip with a dual belt treadmill, they have identified with preliminary data that this population can learn how to respond to trips and slips when undertaking a simulated falls challenge task. Falls are an ongoing problem for ambulant adults with CP in Victoria, Australia (at least), with evidence suggesting that falls result in considerable physical and psychosocial consequences (17), with subsequent in decline in physical activity engagement. Thorpe and Levin’s research from UNC has significant implications to those providing care for this population as it suggests that falls may be preventable and should not be considered an inevitable
consequence of CP. Further, it suggests that ambulant adults with CP have the capacity to improve their balance responses to falls risks through training.
Week 3

European Academy of Childhood Disability (EACD) conference, Amsterdam, Netherlands

Pre conference symposium – Transition to adult care.

I attended a half-day pre-conference symposium on ‘Transition to adult care’. The symposium aimed to ‘discuss current knowledge in this field, aiming to encourage future research and international collaboration. Research findings on a broad range of topics will be presented: from the epidemiology of physical and mental health, participation restrictions, and environmental factors to the (cost) effectiveness of developmentally appropriate interventions for emerging adults with disabilities’.

Overview

Dr Marij Roebroeck, Rotterdam, commenced the symposium by providing an overview of transition issues. She stated that due to an increase in survival rates and life expectancy for those with childhood onset disabilities, more adolescents than ever have chronic disabilities. It is estimated that >500,000 people in the US alone are currently transitioning from paediatric to adult services.

Young adults with developmental disabilities may struggle with issues in the

- Social domain
- Physical domain – more pain, fatigue, less flexibility, poor physical function overall
- Cognitive domain
- Emotional domain

Parental role in transition

There is complex interaction between all these domains for the young person with disability, compounded by concurrent challenges throughout the transition period by parents. Dr Christina Akre (Switzerland) stated that there had typically been less attention on the role of parents in the transition period for their children, yet they are a vital component. Overprotective parenting can be associated with less optimal health outcomes for young adults with disabilities. Conversely, under protective parenting is also problematic. Parents may also lack the tools to assist their adolescent develop self-efficacy into adulthood (18).
Proposed beneficial elements of transition (from adolescence to adult health services)

Dr Allan Colver, from Northumbria Healthcare UK, delivered a presentation on elements of effective and efficient transition programs throughout the UK for young people with chronic conditions (19, 20). He summarised that the following were proposed beneficial features:

- Meet adult team before transfer
- Age-banded clinic
- Appropriate parent/carer involvement
- Transition plan – written and updated
- Promotion of health self-efficacy
- Key worker – advocate for the individual
- Team approach – integrated working
- Life skills training
- Transition coordinator (at managerial level)

CP follow up (CPUP), Sweden

Dr Elisabet Rodby-Bousquet, a physiotherapist and researcher at the Centre for Clinical Research Västerås, Uppsala University, and Lund University and national coordinator for the CPUP (CP follow up http://cpup.se/in-english/) program in Sweden spoke about the use of CPUP to collect relevant data for the management of young adults with CP – with recent inclusion of falls history and Mini BESTest data, an abbreviated test of static and dynamic standing balance (http://www.rehabmeasures.org/Lists/RehabMeasures/DispForm.aspx?ID=1132). Adults with CP can self-refer for inclusion on the data base. In Sweden, registries are all inter-connected between health services, with access available to data bases for researchers to analyse data. Consumers (adults with CP and/or their carers) have been included in identifying what important and relevant outcome measures should be collected on the data base. A ‘traffic light’ system alerts health professionals to when action is indicated for an identified issue in the data, such as an increase in contracture (reduction in passive range of motion beyond ‘normal’ values relevant to gross motor function level - http://cpup.se/wp-content/uploads/2013/07/CPUPcritical_valuesROM20130209.pdf).

Highlights of the EACD conference

I was particularly interested in programs and strategies to enhance physical function (functional mobility, strength, aerobic capacity, endurance etc) in adults with cerebral palsy. A selection of relevant platform presentations and workshops that I attended in conjunction with the conference are outlined below.

Adult Cerebral Palsy Clinic, Michigan, USA

Presentation by Professor Ed Hurvitz, Physiatrist, Adult Cerebral Palsy Clinic Department of Physical Medicine and Rehabilitation, University of Michigan Medical School. In Michigan, an Adult Cerebral Palsy
The focus of the clinic is not to ‘fix’ problems, but to optimise medical status (where relevant) and enhance participation (https://www.youtube.com/watch?v=6iZ5A8vySJA).

Professor Hurvitz’s clinic is staffed by

- Adult physiatrists (rehabilitation physicians)
  - Connections with Neurosurgeons
    - Orthopaedic surgeons
    - Neurologist
    - Obstetricians and gynaecologists etc
- Clinic nurse
- Social worker (available)
- Therapists available (not specifically tied to the clinic)

The Young Adult Clinic, Rotterdam, Netherlands

The Young Adult Clinic (led by Dr Wilma Van der Slot, Rehabilitation physician, Adult Department of Neurorehabilitation, Rijndam Rehabilitation Institute, Rotterdam) is targeted at those between the ages of 18 to 25 years with neurorehabilitation needs. However ongoing care is available through associated clinics overseen by Dr Van Der Slot in the Adult Department of Rehabilitation (i.e. patients do not have to leave this service at 25 years old).

The aims of the clinic are to

- Continue rehabilitation from childhood to adult services
- Monitor and treat the medical condition
- Education re long term consequences and advice on prevention
- Achieve life skills to optimise autonomy
- Improve daily living and participation

Surveying their adult with CP population, they identified the following information needs:

- Cause of CP (34%)
- Consequences of CP (43%)
- Prevention of complications (35%)
- Contact with peers with CP (25%)
- Links to the CP Association (13%)

They use the Rotterdam Transition profile to assist in guiding where the young person is on their transition journey and focus interventions. This tool considers aspects of Participation (education and employment, finances, housing, intimate relationships, transportation, leisure activities) and Health Care (care demands, services and aids, rehabilitation services).

The overall treatment program offered at Rijndam consists of:

- Consult and advice: intake and follow up
- Outpatient rehabilitation treatment program:
  - Individual
The treatment modules of the Group program are:

- Managing your life e.g. self-efficacy, communication skills, taking responsibility
- Independent living and housing e.g. budgeting, finding accommodation, household tasks
- ‘At work’
- Friends, relationships and sexuality
- Healthy lifestyle

Modules are typically delivered late afternoon or evening to optimise attendance, in small groups (6-9 participants), over 6-10 sessions, with 2 facilitators with skills to match the content (e.g. 2 of social worker, occupational therapist, physiotherapist).

Given the focus of this report, I will provide additional detail regarding the ‘healthy lifestyle’ module of the interventions. Of note, motivational interviewing is an important component of the behaviour changes promoted throughout the group program.

The aims of the healthy lifestyle module is to

- Permanently increase physical activity and fitness levels and reduce sedentary time by promoting behavioural changes towards a more active lifestyle
- To promote healthy food intake and body weight

There are four components of this module

1. Fitness training
   a. 12 weeks of 2 sessions per week
   b. Training aerobic endurance, aerobic interval and strength
   c. Progression towards independent sustainability
   d. Continuation of program independently

2. Sports counselling
   a. Sports counselling (2-4 sessions of 30 mins) – interests, preferences
   b. Individualised sports advice and sports specific training
      i. Matched to interests and abilities
      ii. Practice of skills
      iii. Identification of barriers and facilitators

3. Dietary counselling
   a. Identification of healthy nutrition and body weight
   b. Diet diary and measuring of body fat

4. Counselling on physical activity behaviour
   a. Face to face individual counselling sessions up to 1 year
   b. Personal coach: counsellor on physical behaviour
      i. Encourage physical activity
      ii. Discourage sedentary behaviour
      iii. Balancing load and load capacity, including sleep
Multimorbidity in middle aged adults with cerebral palsy (poster), Cremer, Hurvitz and Peterson, Michigan USA

A clinic-based sample of 435 US individuals with CP between the ages of 40-60 years old had their medical records reviewed to identify the prevalence of a range of chronic medical conditions such as osteopenia/osteoporosis, hypercholesteremia, hypertension, asthma, arthritis, coronary artery disease, diabetes, stroke, myocardial infarction. Prevalent multi morbidity was found in 57.8% of the sample.

The most prevalent multi morbidity combinations were
- Hypertension/osteoarthritis
- Hypertension/osteoarthritis
- Osteoarthritis/osteoarthritis
- Hypertension/asthma

There was significant difference in prevalence of multi morbidity between obese and non-obese adults with CP within the same GMFCS Level. There was a significantly greater prevalence of multimorbidity among non-obese people at GMFCS Level IV and V compared to non-obese people at GMFCS Level I-III. We do not have equivalent data available from an Australian adult CP population.

Exercise and musculoskeletal health in cerebral palsy: Mechanisms to prescription, Dr Mark Peterson, USA

Cerebral palsy is a condition characterised by chronic neural inflammation, exaggerated sedentary behaviour, abnormal musculoskeletal development and muscle spasticity. Those with CP have underlying muscle pathology and accelerated functional decline. As a result of the developmental disability, they have impaired myogenesis characterised by decreased mitochondrial density, and muscular fibrosis, plus insulin resistance comprising incomplete beta oxidation and ceramide biosynthesis. Conditions associated with aging in the adult with CP are physical and cognitive frailty, diminished aerobic capacity, sarcopenia, weakness, functional deficit, and fatigability. These conditions are exacerbated by sedentary behaviour and a high fat diet in many western countries, such as the US and Australia.

Dr Peterson provided an overview of an alarming incidence of elevated cardiovascular disease, arthritis, asthma and type 2 diabetes in a cohort of US adults with CP, in conjunction with changes in muscle pathology and accelerated functional decline (16, 21-23). Age, greater disability, physical inactivity and obesity escalate the risk of chronic conditions. The cumulative incidence of each of the cardiometabolic diseases in a three year follow up study of adults with CP was:

- 11.6% for diabetes mellitus
- 34.4% for hypercholesterolemia
• 28.9% for hypertension
• 13.2% for cardiac dysrhythmias
• 6.0% for atherosclerosis

He argued that many of these chronic diseases are preventable in those aging with CP either through lifestyle modifications, and/or optimising medical management and monitoring. It is highly likely that similar multi morbidity exists in adults with CP in Australia.

The impact of functional anaerobic and strength training on muscle volume, strength and functional capacity in young adults with cerebral palsy, J. G. Gillett, Queensland, Australia

There is now evidence to suggest that children and adolescents with CP can reverse some of these risk factors for chronic disease, with the potential to improve muscle volume and strength, and functional outcomes (24). Muscle volume plays an important role in metabolic processes within the body. Insufficient muscle volume therefore adds to the risk of chronic diseases. However, whether this holds true for adults with CP is unknown.

Previous evidence has suggested that although improvement can be achieved in controlled muscle contractions (strength)(25), we don’t know the mechanism underpinning this change (morphology, architecture, neuromuscular) and there is no evidence that improving strength results in improvement in functional capacity and physical activity performance. Preliminary results of a pilot study investigating a new intervention (FAST-CP) was provided by Gillett and colleagues. As a result of a 3 day/week, 12 week program that included strengthening exercises and functional anaerobic exercises, muscle volume increased significantly (hypertrophy), isometric strength and functional capacity also increased.

What is sedentary behaviour in adults with cerebral palsy?
A.C. Balemans, Netherlands

The cumulative risks of sedentary behaviour was also explored by Balemans et al, from the Netherlands. Their group found that breaking up sedentary behaviour (after every 20 minutes of sitting) requires an activity like walking (2 minutes) both in the general population and persons with CP able to walk without assistive devices. However, for persons with CP walking with assistive devices, or unable to walk but able to stand (GMFCS Level III and IV), standing seems sufficient to break up sedentary behaviour and minimize negative health effects.

This information is important for those working with this group in order to optimise health in adults with CP. We need to encourage those with limited ambulation capacity to stand and walk to reduce adverse health risks of sedentary behaviour.
Profiles of fatigue severity and variability among individuals with cerebral palsy, L. Brunton, Calgary, Canada

Fatigue is a common impairment experienced by adults with CP, frequently associated with other mobility impairments (26, 27). In this study, 130 Canadian young adults with CP, mean age 18 years, self-rated the severity and impact of fatigue on their daily life using the Fatigue Impact and Severity Self-Assessment or FISSA (28). Thirty-eight percent of those at GMFCS level I reported average fatigue as moderate to severe. Fifty-three percent experienced fatigue on three or more days in the previous week. Sixty-eight percent of those GMFCS II-V reported average fatigue to be moderate to severe with 78% fatigued on three or more days in previous week. On an average day 92% reported they were fatigued at least a quarter of the day or more.

These results suggest that fatigue is a common problem, experienced by ‘young’ adults, and experienced by those with relatively minimal physical disability (GMFCS Level I). It is likely that similar fatigue is experienced by adults with CP living in Australia, however validation of this tool needs to occur to increase our confidence in application. It also suggests that strategies should be put in place to assist young adults with CP manage their daily fatigue to be able to optimise participation in physical activities.

A model of service provision for adults with CP, Association Paralysis Cerebral, Almada Seixal, Portugal

*Personal meeting with Filipa Moita de Deus, Physiotherapist,*

Services are available to adults with cerebral palsy who live in the geographical region covered by Almada Seixal (Lisbon region) in Portugal. Adults with CP can self refer to the centre, or be referred by a GP or rehabilitation physician (more commonly). It is not time limited, and token payment is required dependent on ability to pay. The centre provides services for about 40 adults, of whom 30 have CP diagnoses, with the average age being 22yo, GMFCS Level III-IV. Transport is available if required (user pays).

Staffed by physiotherapists, psychologists, social worker and a sensory optimisation therapist (focused on autism interventions), the centre offers a range of group programs focusing on issues such as

- Socialisation and participation
- Adaptive physical activity
- Relaxation and stimulation
- Gardening
- Activities of daily living

Participants are allocated to groups depending on their needs and cognitive ability and allocated a case manager from the staff. They changed from offering individual treatments to group programs focused on participation issues recently as they had noticed a tendency to promote dependence on
centre staff by participants when individual therapy was offered. However, individual care is also available to meet specific goals (maximum 1x/week). The main challenge for therapists is providing equipment or updating equipment, as in Portugal, a medical doctor is required on site for funding approval. They are now lobbying government to support this appointment.

The centre also offers a range of informal social/leisure activities, some with a fund-raising focus for family and friends also. For example, boat trips, fun run, evening trips to clubs/bars, gala, summer camps spring camp.
Week 4

Sunnaas Rehabilitation Hospital, Norway

Hosts Prof Reidun Jansen, physiotherapist and researcher, and Dr Grethe Maanum, Head Rehabilitation Physician, Department of Physical Medicine and Rehabilitation.

Sunnaas Hospital is a hospital in Nesodden, Norway, and a health trust under Helse Sør-Øst. Sunnaas is the country’s largest specialised hospital in physical medicine and rehabilitation with specialist multidisciplinary services for those with complex disability such as spinal cord injury, stroke and adults with cerebral palsy. They also have active research programs operating in conjunction with the University of Oslo.

Sunnaas offers both inpatient and outpatient services for adults with CP. Those with CP can be admitted for a specific rehabilitation purpose for 3 days, 5 days or a maximum of 10 days. Rehabilitation programs are individualised (patients can self-refer, although most referrals come via GPs) and may focus on issues such as review of mobility status (exercise, gait aids, spasticity management), driver training programs, chronic pain management, or intensive rehabilitation to achieve a specific participation goal. Coupled with clinical programs, is a dedicated research program that currently strives to ensure best practice. For example, they are currently tracking the mobility outcomes of young adults who may have had Single Event Multi Level Surgery (SEMLS) as a child. We do not know if that surgery (not available 20+ years ago) will change the prevalence of mobility decline currently experienced by around 30% or more of ambulant adults with CP. This research is also required in Australia.

Prof Reidun Jahnson presented a summary of key findings from the Norwegian CP database (currently only has those up to age 15 years entered into it) that indicates some changes in prevalence of CP subtypes now found in Norway, and implications for the future provision of rehabilitation services by Sunnaas. They may advise review by rehabilitation consultants on an annual basis for adults with CP at GMFCS Level III-V, every second year for those at GMFCS Level II, and every third year for those at GMFCS Level I. Given the expertise centered within Sunnaas, a discussion about the need to drive education for more rural/remote health providers regarding management of health issues of adults with CP was also explored and is aligned with current Australian need (29).

Note – Beitostølen Healthsports Center (www.bhss.no) provides publicly funded habilitation and rehabilitation programs for Norwegian adults with CP within a framework of adapted physical activities and participation. I was unable to visit Beitostølen on this fellowship, but have previously been able to visit this outstanding mountain-based village facility that provides residential (typically 2 weeks) programs tailored to achieving specific physical activity goals. Sunnaas therapists work closely with those at Beitostølen to provide ongoing evidence-based care for children and adults with CP.
Habilitering & Hälsa (Habilitation & Health), Västra Götalandsregionen, Sweden

Host: Dr Arve Opheim, FOU-chef, Förvaltningskansliet

There are around 200 new cases of CP born every year in Sweden.

This service provides health interventions for those with disability (such as cerebral palsy), including those who are hearing and vision impaired. It is a regionally funded, outpatient only facility, with a focus on adults at the location that I attended. People can self-refer or be referred by a GP or physician.

The service also acknowledges the importance of evidence based practice in providing high quality health care, with some research funded as part of the programs delivered. I met with a group of clinicians (occupational therapist, physiotherapist, rehabilitation physician) who were also undertaking research activities into optimising health care for adults with cerebral palsy.

Research and clinical focus included the following topics:

1. Balance training and falls prevention in adolescents/young adults with CP
2. The impact of cognitive ability on occupational performance in CP
3. Health and social integration of adults with CP in Western Sweden

Adults with CP who are GMFCS Level III-V more frequently use the service. They are keen to have a systematic way of following up adults with CP, across all GMFCS levels and are inviting adults with CP, birth years 1959-1978 (n=400) to return for a one off assessment.

Of particular interest was the impact of mental fatigue on adults with CP being able to engage in meaningful occupations (work, study, leisure activities). Lena Bergqvist has been utilising a cognitive orientation to daily occupational performance approach (CO-OP approach) to train successful participation. Subtle cognitive dysfunction (such as difficulty focusing, initiating, terminating, memory, sorting impressions) are particularly evident in those with ‘invisible’ CP (GMFCS Level I) that may prevent a person engaging in all aspects of life, including physical activity. Through this approach, Lena has had some success in assisting those with subtle cognitive dysfunction achieve their goals such as tying shoe laces, cooking meals and swimming. This often ‘invisible’ consequence of relatively ‘mild’ CP needs to be considered when referring adults with CP to community physical activity programs.
Conclusions

The main goal of my fellowship was to observe programs that promote physical function in adults ageing with CP either as stand-alone activities, or embedded within an overall ‘life skills’ program promoting physical health and wellbeing in this population. This is needed due to a recognition that health services in Australia for CP have traditionally been very paediatric-focused, and now 3 in every 4 people living with CP are over the age of 18.

To achieve this goal I needed to investigate not only what health service models were delivered in other countries, but how they prepare adults with CP to take responsibility for their own health needs. I had an opportunity to observe a range of programs that had been developed as solutions to challenges that their local population had experienced and applied within their own health structures. I also had the opportunity to observe research programs that are investigating optimal ways of providing services to this population – such as the Residential Immersive Life Skills program or Teen Transition Program, or investigating components of health programs designed to optimise outcomes – such as the ‘slips and trips training’ at UNC, or fatigue measurement and management in Canada.

Throughout my fellowship I had an opportunity to reflect on what I know of health services for this population in Australia. Some things we do very well, but there is scope for improvement to meet the needs of this population. Most people who shared their knowledge and experiences with me were passionate about providing high quality health care for adults with CP. It frequently had been as a result of this passion and enthusiasm that their health service existed in its current form. However this learning experience was also an opportunity to share my knowledge and experience from Australia, of mutual benefit and ultimately beneficial for the patients that we all care for.

Overall I was impressed with the level of interest and activity in providing health services for adults with CP in the countries that I visited. Once a ‘forgotten’ group, their voice and needs are now being heard. Five years ago I went to an international conference on CP. Only 3 papers were relevant to the adult population out of more than 100. At the EACD conference in Amsterdam this year, there were at least two full sessions and a pre-conference workshop focused on issues pertinent to the adult CP population. This is heartening to see, but well overdue.
Recommendations

The following recommendations are offered as a result of my observations throughout my fellowship:

1. Preparation for ‘transition’ to adult health services should start early (in adolescence), and be afforded time and focus, rather than as an ‘add on’ or something that occurs after the child exits paediatric care. Ideally, transition programs should commence in the early teen years.

2. Transition programs that finish in early adulthood, with no explicit articulation with comprehensive adult health services are not recommended.

3. By offering physical activity programs within community gymnasium (non-health) settings, it ‘normalises’ the program, and removes it from a ‘hospital’ setting which many people with lifelong disabilities may not recall fondly.

4. Although community based physical activity programs may suit those with less disability, ready access to onsite therapists may assist in trouble shooting issues that arise – either physical challenges or mental challenges that inhibit participation for those with greater disability.

5. Adults with CP experience significantly greater risk with respect to chronic disease. Strategies to identify and reduce prevalence of chronic disease are urgently required at a community level through regular health promotion activities.

6. Primary care providers delivering health services urgently need up skilling in managing adults with CP to enhance their ability to provide an informed and appropriate service to meet their needs.

Where to from here?

To advocate for change we must review current models of health service delivery. This must be done with the input from adults with CP themselves. Current health programs for adults with CP are fragmented and vary from region to region and state to state throughout Australia. There are opportunities available with my local health network community, in state and national research programs, and in particular, the National Disability Insurance Scheme (NDIS). A review of health services currently offered both to adolescents (in paediatric care) and adults with CP is warranted. Parents of adolescents with CP should be included in this review to ensure that the views of all stakeholders are considered. In the short term, I will meet with local health service providers of transition clinics and/or young adult complex disability clinics to identify a sensible way forward that allows greater capacity for high quality services for adults with CP. I will also meet with colleagues at local disability services to identify strategies to optimise service delivery for this population.

With the current model of health care in Australia, many adults with CP with lesser disability (GMFCS Level I-III), must seek health services from their local general practitioner, or local community health centre for therapy input. The need for sufficient knowledge by health professionals regarding age-related health consequences experienced by adults with CP was highlighted in my fellowship. I am fortunate to have several opportunities to promote my findings regarding optimising health service access and evidence-based interventions for adults with CP. This will occur via curriculum renewal for undergraduate and post graduate health professionals at Monash University, and nationally through the Australian Physiotherapy Association’s and Australian College of Physiotherapist’s professional development programs.
There are currently changes underway in how services are provided for adults with permanent disabilities such as CP through the roll out of the NDIS. Given that physical activity programs may well be offered within the ‘participation’ model aligned with the NDIS, I will also ensure that undergraduate health professionals receive experience in NDIS service delivery prior to graduation, to assist in NDIS workforce development, through my own workplace and interstate collaborations.

A number of international programs offered physical activity for young adults with CP through community gymnasiums. Although this model does occur in Australia, to my knowledge programs are generally generic (are not evidence based), unsupervised (from a therapy perspective) and participants must exercise relatively independently. Canadian programs generally provided indirect supervision from therapists, and offered ‘buddy’ programs using volunteers. Evidence now suggests that aerobic and anaerobic elements are critical for optimal health outcomes. I will explore the feasibility of recreating this model at a local level.

I also have an opportunity to present findings of my Churchill fellowship through the national Australian Physiotherapy Magazine (‘In Motion’ – June 2017, page 33), and future national Australian Physiotherapy Association and international conference presentations.
References

Appendix 1

GMFCS 1
Can run, jump and climb stairs without issue, but speed, balance or co-ordination are impaired.

GMFCS 2
Can walk and climb stairs using a rail but issues with walking on uneven or inclined surfaces or walking in crowds or confined spaces.

GMFCS 3
Can walk on level surfaces with assistive device but a manual wheelchair used most of the time.

GMFCS 4
Capable of walking with a walking frame but mostly relies on wheeled mobility at home and when out.

GMFCS 5
Little or no voluntary control of movement. Maintaining anti-gravity head and trunk postures difficult. All areas of motor function limited. Usually needs to be transported.

GMFCS Gross Motor Function Classification Scale
This scale was originally designed to classify children with cerebral palsy according to their gross motor function. The Society has extrapolated this scale beyond children so that information gathered in our research, “CP through the Life Span” will allow our members to relate the research data for people in a similar GMFCS group to themselves.