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# Self-Management of Chronic Fatigue Syndrome in Adolescents

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## Abstract

Chronic fatigue syndrome (CFS) or myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a condition of unknown aetiology that commonly follows an infection. There are no known predictors for recovery or established treatments. At the Royal Children's Hospital (RCH) in Melbourne, Australia, the majority of young people with CFS are provided with symptom management and lifestyle guidance in an outpatient setting. However, for some, educational or social issues preclude progress and for those who request this assistance, since 2012, the Victorian Paediatric Rehabilitation Service has offered an Intensive Self-Management Program. For this program, participants engage in both group and individual sessions, attending 3 days per week for 4 weeks in small groups of 3–4. Interdisciplinary input is from Occupational Therapy, Physiotherapy, Education and Psychology to assist with goal setting and strategies. Outcome measures are obtained at initial assessment, 6 weeks and 6 months post-program. Support is offered for 12 months post-program. For both the outpatient program and the intensive program the outcomes and feedback from patient and family has influenced the approach and focus. This chapter outlines the current approach and how it has evolved over time.

**Keywords:** adolescent, chronic fatigue syndrome, management, rehabilitation, outcomes

## 1. Introduction

Chronic fatigue syndrome is a condition of unknown aetiology that commonly follows an infective process in young people. There is a new onset of fatigue for at least 3–6 months that is not relieved by rest and not explained by other medical conditions. Post-exertional malaise, cognitive difficulties and unrefreshing sleep are present. In addition, a variety of somatic symptoms are commonly present such as headache, abdominal or muscle pain, as well as flu-like symptoms without fever, and symptoms associated with orthostatic intolerance [1–5]. The key features and symptom patterns in young people have remained consistent [6–9]. Anxiety and depression may also be present but when compared with population levels, were only mildly increased in prevalence, and generally did not precede the illness. They were understandably associated with diagnosis delay, not being believed or social isolation [8, 10].

There is currently no defined treatment, as the underlying pathology is not well understood [11]. Similarly, there are no known predictors for recovery [10]. When this illness occurs during childhood and adolescence, it is at a period of significant

developmental changes. In those that report recovery, the duration of illness has mean of 5 years and range 1–16 years [10]. With long-term follow-up, there is a significant proportion that does not report recovery [10, 12, 13]. There is disruption to their educational, social and physical activities, which create huge challenges for the young people and their families [14, 15]. It is the commonest cause of reduced time at school [16, 17], and has a significant impact on educational functioning [18]. Hence, in addition to managing symptoms, strategies for coping with this chronic illness and its impact on the young person and the family have been central to its management in this clinic [10]. Although there are other chronic illnesses during childhood and adolescence that have physical, emotional, cognitive or educational impacts [19–23], this illness does affect all these areas. Neglecting these aspects can compound the effect of the illness, and impact on the developmental tasks of adolescence or the transition to or from adolescence. Parents have a role in helping navigate these tasks, as well as trying to manage a child who is unwell [19, 20].

This chapter will outline the management strategies that have been employed in an outpatient setting that have been guided by feedback from young people over a period of more than 25 years; a description of the development since 2012 of an intensive self-management program for those who need additional assistance; and observations about characteristics of participants in the program and their reasons for referral.

## **2. Outpatient management**

### **2.1 Chronic fatigue syndrome outpatient clinic at the Royal Children's Hospital**

The Royal Children's Hospital is a specialised secondary and tertiary referral paediatric and adolescent hospital that services metropolitan Melbourne and all rural areas for the state of Victoria including bordering areas in neighbouring states. Furthest distances require 4–5 h of car travel. Referrals are received from family doctors or from specialist paediatricians. Victoria has a population of 6.3 million and is multicultural. There is a universal health system that ensures citizens can access health care free of charge to the family. There is also a private health system that can provide partially subsidised health and allied health care.

The CFS clinic has been functioning since 1989. In the early years of the clinic the Holmes definition and Fukuda criteria for CFS were available [2, 3, 21]. However, acceptance of the diagnosis in young people was uncommon in the medical fraternity. It was well recognised that Epstein Barr Virus (EBV) infection (or glandular fever) could run a prolonged course during adolescence. Irrespective of whether EBV was confirmed, it was assumed in some cases, that this was the cause of these symptoms. Alternative explanations that were entertained were depression, stress, school refusal or somatisation disorder or the possibility of undisclosed family difficulties. Parents who were anxious due to concern about the unexplained change in the young person were often considered to be contributing to their illness. Hence many who attended the clinic had experienced unsatisfying encounters with the medical profession.

The reported symptoms were very consistent among the young people attending. The presence of post-exertional malaise (PEM), unrefreshing sleep, cognitive difficulties, persistent fatigue and pain (headache, muscle, abdominal) were all almost universally reported. Sore throats and lymph nodes, feeling hot and cold and symptoms later recognised as associated with orthostatic intolerance were very common. These symptoms were consistently reported even though at the time there was no access to this information in the public arena.

Although the intravenous immunoglobulin trial in young people appeared a promising treatment [22], trials in adults were inconclusive [23–25], and approval was not granted for its use. Thus options for treatment reverted to general management strategies for chronic illness. We relied on feedback from young people to inform us regarding what was helpful in their management. The service has since expanded to several paediatricians and access to a 4-week self-management program run by the Victorian Paediatric Rehabilitation Service at the hospital.

## 2.2 Diagnosis

A diagnosis of CFS is made following an extensive history, to confirm the presence of key symptoms, examination and routine investigations to exclude alternative diagnoses. These symptoms include PEM, unrefreshing sleep and cognitive symptoms as well as additional somatic symptoms [15]. Other conditions including school refusal, somatisation disorder, eating disorders, isolated significant depression or anxiety, connective tissue disorders, coeliac disease or endocrine disorders are specifically checked. An adolescent psychosocial (HEADSS) screen is also conducted where appropriate [26]. Passive standing test was not routinely performed initially. However, upon recognition of the association of orthostatic intolerance with ME/CFS this assessment was included [1].

Routine screening investigations included coeliac screen, thyroid function and antinuclear antibody. Serology for EBV or cytomegalovirus (CMV) is routinely assessed or if there was any likelihood of overseas or tropical infections or if the young person had been in areas where Ross River Virus, Q fever (*Coxiella burnetii*), Barmah forest virus were endemic, serology for exposure is also checked.

## 2.3 Management

### 2.3.1 Initial appointment

Following diagnosis, the young person is asked to: rate the most troublesome symptom/s that he/she would like help with; outline his/her aspirations prior to illness; describe current school attendance, interests, and previous participation in sport, the family situation and supports including parental work schedule, and means of transport to school or activities. The young person is provided with a brief explanation of our current knowledge, a plan for managing the most severe symptoms, and an outline of a management plan that the young person would devise.

### 2.3.2 Management plan designed by the young person

The rationale for the management plan is to minimise the impact of chronic illness while accommodating the specific issues associated with CFS. As CFS affects the educational, physical, social and emotional aspects of their life, it is considered important to not neglect any of these areas. This should include some proactive social contact, academic input, physical activity and a commitment to attend something enjoyable outside of home on a regular basis. None of these activities is to be neglected but the proportion does not have to be equal. The plan needs to be sustainable for at least a month before it is reviewed. For example, some physical activity is required to prevent becoming so de-conditioned that they are unsure whether they are weak and fatigued because they are unwell or because muscles are not being used. Social contact is important to ensure that the social learning that occurs during adolescence (how to respond in different situations, what behaviour is acceptable and how to interpret different social situations and how to understand

one's peers) is not neglected. It can be very daunting later when it is expected that these skills have been acquired. Academic engagement is important so that they feel that their life chances have not been destroyed. The regular enjoyable activity outside of home is something that they have chosen to attend because it is 'worth it' and will not result in a prolonged recovery. It removes any prevarication regarding whether they feel well enough, whether they would cope or whether it would be easier not to go. Only if they are unable to move out of bed do they not attend. This hopefully prevents the reluctance to make decisions, to be adventurous or to be reliable.

In addition, young people generally have not had to learn to prioritise their activities during their teenage years but it is needed as developing adults. It is explained that they need to learn this much earlier than most and it is a very useful skill to acquire. Some activities, for example, attending school for an enjoyable subject could fulfil social, academic and enjoyable activities and also require some physical activity. If their important social network was outside of school then there needed to be an effort to engage with that group for a period of time that was manageable. If some young people felt that 'life was not worth living' if they could not play sport, as this was their main social connection, then adjustments could be made. They could be part of the team by 'coming off the bench' for a few minutes or not being required to actively train. They could be moved to a team position that did not require a lot of stamina. On the other hand, for some, physical activity may be a few activities of daily living spaced over the day, or once they are able to do some activity and have increased their strength, they often chose a variety of activities that they enjoy.

Their aspirations (prior to becoming unwell) play a key role in the decisions regarding their education. Attending school for set hours, rather than for specific subjects is difficult to sustain. Reduction in the school subject load to include subjects and teachers they liked, as well as subjects that are pre-requisites for what they want to do as a career is crucial. Trying to keep up with all subjects when only given minimal information is a source of unnecessary stress, and this rarely succeeds. A planned timetable ensures that the arrangements provide some consistency and predictability for the family (and for the teaching staff) and be manageable for the young person. If the symptoms are severe, the extent of 'academic input' may be reduced to reading about a hobby or reading a story that they are already familiar with.

It is explained to the young person that these consequences of illness can be more damaging than the illness itself and can occur with any chronic illness. Neglecting these areas creates significant hurdles to recovery such as: navigating social anxiety and social learning; entering the workforce without a potentially enjoyable, satisfying or more lucrative, less physically demanding job; needing to increase strength, or not having the confidence or resilience to know how they are able to manage their life. The young person is asked to estimate how they can balance these tasks within the bounds of the amount of energy available over the period of a week. The young people make those decisions over the subsequent few weeks and discuss their plan with their parents.

### 2.3.3 Symptom management

Only the most severe one or two symptoms are treated initially. Often treating one symptom such as sleep disturbance, and allowing them to take control of their life with the management plan reduces the severity of some of the other troublesome symptoms. Despite the prominent fatigue, malaise and concentration difficulties, the complaints of headache and sleep disturbance or dizziness and nausea due to orthostatic intolerance, can often be managed effectively.

Difficulties with sleep initiation, sleep phase shift, frequent waking and disturbing nightmares are actively managed with sleep hygiene techniques and melatonin or low dose tricyclic medications such as dothiepin or amitriptyline. Simple migraine prophylactic medications such as pizotifen or periactin are anecdotally effective in reducing the severity of headache. Simple measures such as increasing salt and fluid intake, including electrolyte drinks, and encouraging lower limb exercises and gentle exercise can assist with orthostatic intolerance. Similarly, muscle pain and fibromyalgia can be helped by reducing sleep disturbance and encouraging gentle exercise or physical therapy.

Residual difficulties with concentration, recognition of depression, persistent severe dysmenorrhoea associated with exacerbation of CFS symptoms, ongoing nausea, abdominal discomfort or persistent orthostatic symptoms are usually addressed after review and the implementation of the management plan.

#### *2.3.4 Review appointments*

A 6-week follow up appointment is usually scheduled for review of their plan and whether the logistics are sustainable. Residual symptoms are checked including whether the symptom management is appropriate. Any further queries from the young person are addressed. Once a decision had been made regarding the schedule for education, appropriate explanation, documentation, advocacy, extra support, special provision or special consideration is provided or requested. A specific education program to ensure maximum possible opportunity to participate is therefore implemented. Sometimes this requires a combination of Distance Education and school attendance for 1–2 subjects, or attendance for a few classes with visiting teacher assistance. If necessary, the minimum requirements are negotiated to ensure the year level is passed so that they can progress with their peers. Additional details regarding educational strategies used by the Visiting Teacher Service have been documented [27]. If adjustments to sport schedules are required, these are provided and coaches and staff are usually very accommodating once they understand the reasons for the requests.

Generally 3-monthly reviews are arranged to assess progress, educational issues, symptom management and review of goals. Young people are seen more frequently if necessary. Occasionally young people are followed up by a local paediatrician.

In addition, parents often need help navigating the difficult adolescent period and uncertainties regarding assisting with the tasks of adolescent development in the context a chronic illness that is generally not well understood. The developmental tasks (19) of adolescence may fail to progress during the illness and may need to be addressed during management, or time allowed for some catch up when the young person is well enough. Such tasks can be difficult for any parent to navigate but even more difficult when the young person is clearly unwell and not able to manage some simple activities of daily living.

These tasks include increasing sense of independence and responsibility for their actions, peer relationships, sexual identity and development, assessment of risk, sense of self-worth and hope for the future. Persistent dependence, uncertainty about what is required, social anxiety and withdrawal, extreme caution in making decisions, poor self-esteem and depression regarding the future can be the consequence of the limitations imposed by chronic illness. Parents are not sure if they should be defending, protecting and trusting the young person's judgement or cajoling, setting limits and allowing the young person to make mistakes. Many parents put their life 'on hold' to care for the young person with the attendant complications for the whole family, and this often adds significant stressors. For many young people, doing some small chores that do not require much effort is important in order to be part of the family and reduce tensions with siblings.

For younger patients, there are concerns regarding persistent dependence on parents, and anxiety regarding the illness, such as concerns about what was actually wrong and whether there would be recovery. They worry about managing at school, as well as social anxiety when they are absent from their social network for some time. There may also be depression and a sense of helplessness and powerlessness, especially if some family members, the medical profession or teachers do not understand. In addition, the transition into adolescence and secondary school is exacerbated when they are not able to attend frequently enough to engage socially.

## **2.4 Feedback from young people**

Feedback from young people regarding their management was sought on many occasions over the years and has been reported in detail [28]. This feedback modified management. Feedback affirmed that being believed by the clinician, family and school staff and feeling as if they had an advocate to help them navigate the education system were central to their overall ability to cope and their general well-being. Having a management framework within which they could organise their priorities was seen as key to feeling as if they could have some control over their life again. Of note, assistance with being able to continue with education was valued as important as their medical management. Continuing social engagement as part of their self-management was crucial for continuing social learning. For those where outpatient support has not been sufficient, there is now access to a 4-week intensive self-management program.

## **3. The intensive self-management program**

### **3.1 Background**

In 2012, the Victorian Paediatric Rehabilitation Service (VPRS) at the RCH in Melbourne commenced multidisciplinary management of adolescents with CFS. This followed a state government review of services available for young people with CFS, and the recognition that outpatient services required additional support and a more coordinated approach. A systematic review by Knight et al. [29], of the limited literature available on paediatric interventions, indicated some support for cognitive behaviour therapy (CBT) and limited support for multidisciplinary intervention. However, the quality of these studies, did not allow firm conclusions to be drawn.

Thus it was decided that the new program would have a CBT framework, be goal-focused and strongly encourage self-management. Following ongoing evaluation and feedback, it was noted that some aspects continued to work well, while others needed modification. With the implication that there is no known 'cure', there needed to be a change in approach from the typical rehabilitation aim of assisting with the reduction of suffering as the sole focus. Feedback from families and participants found this approach to be disempowering. This ensured that, rather than being viewed as an illness to be endured it could be a more hopeful, dynamic and positive process. Recovery was possible and at the very least, there could be an improvement in functioning and some participation in important stages of adolescent development.

In the early years of the program, there was minimal involvement of families in program sessions, with the focus solely on the young person and engaging them in self-management. There was some inflexibility and a more rigid approach where all participants were encouraged to engage in activity on non-program days with little individualization of the program. Often participants were too exhausted at the end

of relatively long therapy days to convey to parents what they were keen to practise and how they needed to be supported at home. This resulted in confusion within families about plans and expectations on non-program days, repetition of the same information to multiple people and reduced understanding by parents of the clinical reasoning behind the program. This was an unfortunate approach and much was learnt from patients and families at this time. More flexible, individualised guidance in setting up a management plan was preferred. It allowed for flexibility, review and adjustment when progress occurred. It was noted that family involvement was required to improve participant engagement and successful carryover of effects after the program.

In addition, increasing recognition of the association of postural orthostatic tachycardia syndrome (POTS) in the referrals required a change in the focus of exercise therapy within the program. Cardiologists became an important part of the medical management alongside the CFS medical team.

### **3.2 Overview of the current 4-week intensive self-management program at RCH**

The aim is to encourage ongoing, self-directed learning and management of the illness, so that participants and families have the strategies and confidence to reduce the chaos, uncertainty and loss that underpins living with CFS during adolescence. They are encouraged to re-engage in key areas of life that have been neglected or problematic.

The VPRS CFS Self-Management Program runs for 3 days per week, for a 4-week period and is located in an outpatient setting within the hospital. Four staff, an occupational therapist, a physiotherapist, an education consultant and a clinical psychologist provide interdisciplinary care. Each therapist covers 2 days of the 3-day program. They also meet weekly with referring doctors to discuss participant progress.

A typical day is runs from 9.30 am to 3 pm. Each participant identifies his or her own goals and these are used to establish a framework to work within over the 4 weeks. They continue to work with this framework after the program.

The program is structured around individual and group sessions. The structure of the sessions allows for key content to be explored and built on over the weeks. During the non-program days (two weekdays and the weekend) they are encouraged to practise and to implement what they have learned. Participants are encouraged to be open-minded and to consider new ways of looking at and living their life.

For many participants and families it is an enormous undertaking to attend the program. It varies how feasible it is to practise new skills on non-program days. For most, the opportunity to try out new activities and routines in a considered, modified way is attainable. For some, however, the goal is to engage during program days, learn the theory and skills within the three-day structure and have quiet days in between. Much of the practising then occurs post-program when they can spread their energy availability over a week at a less intense pace. This approach is flexible, individualised and sustainable as they learn self-management tools that continue well beyond the four-week program.

### **3.3 Assessment**

#### *3.3.1 Inclusion criteria*

Participant inclusion criteria used by referring doctors from the CFS Outpatient Clinic is as follows:



10–18 years of age.

CFS is the primary diagnosis and the patient accepts this.

Display motivation to engage in the intensive nature of the program.

Enrolment in education.

Physically able to manage 3 days per week of engagement for 4 weeks without significantly worsening their symptoms as a typical program day requires participants to walk approximately 700 m to access the treatment areas from the hospital entrance.

Tried doctor-led outpatient guidance in the first instance.

Stable mental health

This assessment consists of a 45-min psychology assessment, 45-min education assessment and a combined 90-min occupational therapy and physiotherapy assessment. The patient attends the assessment with at least one parent or guardian present. In addition to detailed assessment about CFS, there is exploration of the young person's motivation to participate in a group program setting and their attitudes and beliefs about CFS are recorded. This is to ensure a group program is a suitable 'fit' for the young person. The philosophy and structure of the intervention is explained and goal setting is completed.

We have also noted that if any of the above criteria are not met, the likelihood of positive engagement is poor. In particular, where motivation to participate is parent rather than patient led or if CFS is not the primary diagnosis, the group dynamic is affected.

It is clear that the intensive program is not suitable for all young people with CFS. Those who are unable to attend the program in person for all the required days without significant worsening of symptoms are not appropriate. These patients are encouraged to continue with the doctor-led outpatient guidance in conjunction with a physical therapist that can provide therapy in time frames and intensities that are a better fit for the patient.

Currently the program is moving towards offering pre-program conditioning and guidance to streamline the process of starting a program so that many months are not spent with the young person in limbo.

### *3.3.2 Baseline and outcome measures*

Outcome measures are completed at initial assessment, 6 weeks post-program and 6 months post-program. The current outcome measures are:

- Canadian Occupational Performance Measure (COPM) [30]
- Depression Anxiety Stress Scales (DASS) [31]
- Physical measures—Day 1 sub maximal treadmill test and plank hold
- School attendance

From 2012 to 2018, the psychological measure was the Beck Youth Inventories measure [32].

### *3.3.3 Assessment decision*

The VPRS therapy team meet post-assessment to discuss findings. Provided the patient meets inclusion criteria and the family are keen to participate, an offer is

made to participate in an upcoming program. The wait list is usually 2–4 months. If either the family or the VPRS therapists do not feel the 4-week intensive program is an appropriate match for the family, alternatives in the community are explored. We have found that these alternative options are particularly appropriate in cases where families find it too difficult to be at the hospital for the required time due to work, sibling needs or their own health issues.

In addition, as several participants are in each program, every effort is made to match participants based on age, educational stage and likely group dynamic and, to a lesser extent, current function and engagement in life.

#### *3.3.4 Pre-program information and program readiness*

Program information is emailed to families soon after an offer is made. This information includes logistics as well as a proposed timetable so that families can forward plan. A blank activity record is also sent to be completed the week prior to the program so that the therapy team have a current record of how the participant is spending each day with regard to sleep, activity, social contact and study.

To give participants the smoothest transition to the program and ultimately an effective intervention, a VPRS therapist via telephone, or in person, conducts a pre-program readiness interview, in the 2 weeks prior to the program. The previously identified program goals are clarified and changed if requested. It has been noted that without adequate time to prepare mentally and physically for the program, it takes longer for participants to settle in and co-operate with the program's agreed expectations.

### **3.4 Program content**

#### *3.4.1 Pacing and energy conservation, sleep, leisure*

Participants work as a group to learn and implement core functional activities of daily living into their weekly schedules. Topics covered include sleep hygiene, balancing activity, leisure, memory and concentration, diet, pacing and energy conservation and setback planning. Participants learn to formulate a weekly planner, where they plan a balanced week of both 'need to do' activities and 'want to do' activities. This is to ensure that they plan a manageable week in line with their current baselines of their CFS physical and mental capabilities. During the program, participants embark on an outing as a group in order to practise these concepts and strategies, as also planning and cooking a meal to do the same.

#### *3.4.2 Goal setting*

Goal setting sets the framework for the program. Goals are revisited regularly and progress tracked. Weekly individual goal review and progression sessions occur with the Physiotherapist and Occupational Therapist. Weekend planning and weekend review sessions, help to build skills of incorporating structure into to daily routines. These are group sessions and peer feedback is encouraged. In the planning sessions participants generate ideas and suggestions of what is helpful to include in weekends. A key feature of weekend planning is to include leisure activities that the young person has previously enjoyed or is keen to participate in. Weekends are also used for practising independence, perhaps in driving lessons with a parent, taking public transport or helping cook a meal. They are also important opportunities for achieving sleep routine consistency and pacing activity. They also provide an opportunity to practise challenging thoughts and to practise mindfulness and clear communication with family and friends.

### 3.4.3 Education

Educational engagement is once again identified as the most significant part of life affected by CFS. The effects in a young person's life when school attendance is limited or absent are devastating, affecting self-esteem and mood from social isolation and compromised learning outcomes. Prior to the program the education consultant liaises with participants' school contacts to establish communication. It has been noted that the variability in school engagement prior to the program improves afterwards with schools taking a much greater interest in learning about CFS and how they can assist the young person to engage in school.

During the 4-week program, eight supervised group-learning sessions occur in the Education Institute Learning Space at the hospital where participants undertake private study and complete activities set by their school. They also apply memory and concentration techniques learnt during the program to assist with concentration, pacing, homework and study management. Four individual consultations provide strategies and recommendations for support upon returning to school. These are discussed with the student, family and school personnel. The education consultant continues to support participants and schools well beyond the program to assist with challenges that inevitably arise.

### 3.4.4 Psychology

The participants receive group psychology sessions weekly wherein they learn the following: (1) understanding how CBT can help; (2) monitoring and challenging thoughts; (3) understanding emotions, stress, anxiety and mood; (4) relaxation strategies for stress and anxiety; (5) coping strategies for low mood; (6) building motivation and (7) engaging in assertive communication skills and family conflict management. In addition to this, they receive individual psychological reviews each week. This builds on the group session work and focuses on assisting with interventions for the interaction between CFS symptoms and mental health.

### 3.4.5 Physical therapy

The physical therapy component of the program consists of individualised goal setting and program planning based on the initial assessment. It is refined and revised as the program progresses. There is a group theory component as part of some sessions, covering topics such as chronic pain, Postural Orthostatic Tachycardia Syndrome (POTS) and progressing movement and exercise safely in order to minimise the likelihood of post-exertional malaise.

Post-exertional malaise (exhaustion and malaise after activities, either physical or mental, that previously were tolerated well) is a hallmark feature of CFS. It greatly reduces young people's ability to participate in physical activity as previously enjoyed.

Early in the program, participants begin an individualised movement program, delivered in either an individual or small group setting. This starts with gentle stretching and strengthening and for those where it is appropriate, short duration cardio activity. Participants and families are actively involved in all decisions regarding types of reconditioning and pathways of progression.

Participants are given a choice of a range of approaches to movement and reconditioning. They are encouraged to choose activities they have previously enjoyed and would like to incorporate such as shooting goals in basketball outside for a set time with another participant, or completing movements on the pilates reformer

machine. Movement tasks are incorporated into weekly plans and are aimed at being meaningful in the young person's life such as walking 5 min to the local shops to buy ingredients to bake or taking the family pet for a walk around the block. Some participants much prefer this approach while others are more aligned with an athlete rehabilitation approach with more conventional exercise. Careful consideration and monitoring is applied to all patients.

#### *3.4.6 Postural Orthostatic Tachycardia Syndrome (POTS)*

In recent years, a high number of participants have a diagnosis of POTS alongside CFS. These patients need very specific management in physical therapy sessions. POTS symptoms come on with standing and are relieved when becoming supine. Heart rate increases by 40 beats per minute or more and there can be a blood pressure change. Associated autonomic symptoms include sweating and blueness/swelling in the feet. There are often palpitations, fatigue, exercise intolerance, nausea, near syncope, syncope, 'brain fog' and chronic pain. Doctors may prescribe medications and the exercise component of treatment is critical.

The physical therapy for these patients has four components:

- a. **Lower limb and core strengthening.** Lower limb muscles act as a secondary pump to augment venous return. Those patients who are significantly symptomatic start in a reclined sitting position or even in supine position to strengthen all large muscle groups. Exercise therabands are often used for resistance. As symptoms improve, strengthening is completed in standing and progressed with increasing the number of repetitions and resistance.
- b. **Cardiovascular reconditioning.** For the most debilitated patients cardiovascular reconditioning starts in a reclined position, usually with pedalling a light set of pedals. The progression is to sit more upright with feet out in front on the pedals and then on to a recumbent exercise bike followed by an upright exercise bike as able. Patients do walk short distances for functional purposes but most of the reconditioning is done in sitting position to reduce the orthostatic load. Sessions are initially short duration and low intensity before progressing in both these areas. Intensity is increased slowly with short duration interval work. Significant consideration and respect is given to fatigue levels and recovery rates.
- c. **Standing tolerance drills.** While lower limb and core strengthening and cardiovascular conditioning are developed, some time is devoted, when tolerated, to starting some exercises in standing position. These include heel raises; squats and wall push ups to challenge the body's ability to exercise while standing.
- d. **Additional management.** This includes electrolyte drinks, salt tablets, the wearing of lower body compression garments, raising the bed 10° with the head end higher, and encouraging sitting up with feet flat on the ground rather than lying down during the day. Many patients require medication support to enable the patient to be able to tolerate re-conditioning exercise. When patients present with a POTS diagnosis or have significant orthostatic symptoms, the approach outlined above has been effective. Progression does, however, require a multimodal approach with multidisciplinary input helpful to achieving progress.

Psychology support in POTS patients appears to be very helpful, in particular assisting patients coping with the significant heart rate increases and adrenaline released on upright standing. These physical symptoms mimicking anxiety can be confusing for patients, particularly those where anxiety has not previously been present.

### 3.4.7 Pain

Pain is a common symptom in CFS. This can be headaches, joint pain or abdominal pain. Very often these pains do not respond to medication. Sometimes pain is present due to long periods of physical inactivity. For other patients the protective function of pain is no longer serving that purpose and patients may develop a central sensitisation.

The approach taken in the program in the first instance is to ascertain a patient's concept of pain. Once this has been established, using questioning and simple quizzes, a pain curriculum is developed. While some initial pain theory is covered in the group setting, further exploration of possible contributing factors to the young person's pain is explored on an individual basis in both physiotherapy and clinical psychology sessions. The treatment approach is based on the work of Lorimer Moseley and David Butler of the Neuro Orthopaedic Institute Australasia [33]. Its focus is on understanding chronic pain as one of many outputs of the brain in response to a range of inputs. It seeks to establish the interactions between the mind, the body and the environment and the complex interaction with the nervous system that occurs.

### 3.5 Follow-up

Patients are reviewed at 6 weeks and 6 months post-program. There is weekly email or telephone contact in the first 6 weeks post-program with a face-to-face review at 6 weeks. Patients and families are able to access ongoing support from the team for advice and direction. There is limited scope to offer therapist face to face sessions beyond the program outside of the scheduled reviews. All patients return to the care of their referring paediatrician post-program.

### 3.6 Patient feedback

Feedback is regularly sought from participants—both informally during the program and at follow-up reviews as well as written. More formal feedback has been obtained intermittently. While patients describe learning about pacing, thought challenging and educational tips as being helpful, they overwhelmingly describe meeting other young people in a similar position and feeling like they belong and are supported, as being the most valued part of the program. This often results in participants forming close bonds with each other and many friendships have continued over the years.

## 4. Review of referrals

As the program is resource intense, and many young people are successfully managed in outpatients, it has been important to attempt to identify which ones need the more concentrated input and access to the multidisciplinary team and when the ideal time is to refer. Approximately 25 complete the program each year. It has been noted that the proportion of males (26%) to females referred to the

program reflects the proportion noted over many years of close to 1:3 [10, 15]. However, there was a higher proportion than expected from rural areas. In Victoria, 23% of the population live in the non-metropolitan area, but 42% of participants came from non-metropolitan areas (chi-square 9.19,  $p < 0.005$ ). Rural regions have less access to local paediatricians, additional educational services such as visiting teachers and specialised allied health support is scarce. There were higher proportions of young people participating in the program during year 9 (28%) and year 11 (24%) compared with the other years between grade 6 and year 12. The year 11 students are in their penultimate year of school prior to university entrance exams and year 9 is recognised as a turbulent year in adolescent social development, and the year after which some decisions on subject choices for future careers need to be made. Hence educational issues were a significant stimulus for the referral.

Of note, 44% admitted to >4 h of screen time (phone, computer, television) per day. This would generally be considered excessive but did reflect those who had been unable to increase their school attendance and who had become more socially isolated. It did also become an increasing problem when gaming was involved as this tended to occur late at night and contribute to day/night reversal of sleep cycle and increasing loss of time from school. A higher proportion of males than females saw this as their only social outlet.

POTS was diagnosed in 78% [1, 15] either coinciding with the onset of CFS following an infection, occurring associated with hyperflexibility and having associated CFS symptoms, or apparently developing after the prolonged bed rest or limited activity associated with their CFS. During recent years this has become better recognised, documented and managed but its management has occupied an increasing proportion of referrals. It has generally been poorly recognised by paediatricians and many allied health providers are unfamiliar with how to help especially in the context of the limited stamina of CFS.

From outpatients, it was noted that early referrals to the program were often not appropriate. Young people and their families needed time to understand the illness, develop some confidence that they could plan an appropriate schedule and sustain it, and have an opportunity to improve some of the more troublesome symptoms, such as sleep disturbance and headache. Frequently simple measures for managing POTS or if these were not sufficient, referral to an appropriate cardiologist was important to improve control. Crucially, having a sustainable school program with understanding from school staff and their peers was central to management. Families also needed time to adjust their schedules to a more balanced and sustainable form to assist the young person.

Hence, those who, although they were attending school, struggled with their weekly schedule and balancing their daily activities such as exercise, sleep, school work and social activities needed additional help. Occasionally the family social circumstances made it difficult to attend school regularly. Teachers who were unsympathetic or peers who did not understand contributed to difficulties at school.

Those who were not attending or managing school work, were often very anxious and increasing screen time contributed to further reduction in school attendance. Many found adjusting to avoiding a boom/bust cycle where they would do too much and then take a long time to recover and be very despondent or angry at these restrictions was a significant problem. They felt they needed more support in planning and adapting.

Only a small proportion of the patients seen in the outpatient clinic are referred to the program. As per the feedback over many years, ability to construct a self-management program and guidance to adapt and sustain progress was highly valued. In addition, assistance with planning sustainable education with school liaison was cited as helpful in allowing them to remain socially engaged and hope

that their aspirations were achievable. In essence those referred and reporting benefit from the program where those who needed more support in planning their self-management, more intensive assistance for their POTS but most importantly assistance with their education.

It is clear that as the staff have become more familiar with the illness, and have received feedback that they have incorporated into the program, that the key features that are valued are identical to the feedback the outpatient program has received over the years [10, 28]. Access to physiotherapy especially for the specific management of POTS would make outpatient management easier. An education consultant to liaise with schools is often more acceptable for the school than being approached by a paediatrician, although usually medical documentation and recommendations are required by educational authorities. In addition, the input from a psychologist who has an understanding of the illness and the feelings of anxiety that occurs with POTS as well as the impact chronic illness and disrupted education has on the social and emotional development of a young person can be very helpful. Crucially it is the feeling that they are understood and believed and that they are not the only ones with the illness. Regaining some control over their lives by how they can manage the illness is highly valued.

## **5. Conclusion**

The majority of young people can be managed in an outpatient setting and availability of some of the expertise such as physiotherapy and an educational consultant would greatly assist in management in that setting. This would then free the more intensive self-management program for young people who could not access allied health, needed more guidance for planning or who needed help for family understanding, cooperation with school or help to understand the mental health issues that may accompany chronic illness and social isolation. The acceptance and linking with other young people with an illness that is poorly understood and accepted, has been invaluable.

The program at RCH will continue in its current form of individualised patient plans within a group setting. Involvement of families in key sessions alongside participants has shown to be the most effective way to encourage carryover of improved engagement in life post-program.

Ongoing feedback from young people and their families as well as research findings continue to inform both the outpatient management and the intensive VPRS program. Increasing interest and understanding from paediatricians and allied health staff can only help by reducing the frustration, delay, misunderstanding and access to services for these young people. Assisting them with symptom management, guidance in devising and implementing a self-management plan and assistance in navigating the education system has reportedly been highly valued. Having the added assistance of a multidisciplinary team and intensive program when aspects of this management were not sufficient has been highly valued.

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## **Conflict of interest**

The authors declare no conflict of interest.

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