

Empowering Young People with Chronic Fatigue Syndrome:

Sharing learnings from an MDT lead self-management course.

Victorian Paediatric Rehabilitation Service



MONASH University





Acknowledgment of country

We begin today by acknowledging the Gadigal people, Traditional Custodians of the land on which we meet today, and pay our respects to their Elders past, present and emerging.

We extend that respect to Aboriginal and Torres Strait Islander peoples here today.



Today's Facilitators

Dr Sabine Hennel – Paediatric Rehabilitation
Physician and Paediatrician

A/Prof Adam Scheinberg – VPRS statewide
medical director and Paediatric rehabilitation
physician

Jared Chan – Physiotherapist

Heidi Gilmore - Teacher/Education Consultant

With contributions from:

Dr Elisha Josev – Senior Research Officer and
Clinical Neuropsychologist

Ella Barry – Occupational Therapist

Introduction



Introduction

- Paediatric myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS)
 - disabling condition
 - unknown etiology
 - significant and well-documented adverse effects
- Diagnostic uncertainty
 - estimates varying from 0.1% to 4%
- Challenges
 - no diagnostic biomarkers,
 - no cure
 - anxiety and uncertainty

Chronic Fatigue Syndrome



fatigue



severe headaches



loss of memory
or concentration



sleeping problems



muscle pain



sore throat

Definition: fatigue associated with

- substantial reduction/impairment in ability to engage in pre-illness activity
 - occupational,
 - educational,
 - social, or personal activities
- persists for more than 6/12
- accompanied by sleep disturbance , cognitive impairment and post exertional malaise

OM (institute of medicine USA)
criteria 2015

Chronic Fatigue Syndrome

- Huge impact on young people!!!
- Significantly disabling with long term consequences on
 - self-esteem,
 - career pathways,
 - mental health,
 - education and
 - physical functioning.
- Adolescence is a critical time to connect with peers and CFS often impairs this.



Learning Objectives

- Partnering with clinicians and young people to develop a research program
- Setting meaningful individual goal for young people with CFS
- How to assist young people with CFS to achieve their exercise and participation goals.
- Effective advocacy in the education a training space for young people with CFS
- Supporting Parents and families



The MDT partnership

- MDT approach is supported by the NICE guidelines and in the literature
 - Key is an individualized collaborative care plan
 - individual goal setting
 - A self-management approach keeping young people goals at front and center
 - Ref Hiremeth et al 2022, NICE
- Basis for our self-management program (6 yr history)
- Through partnering with young people – learnings to share
- Research partnerships



Partnering
with young people
with CFS to
develop a research
program –
learnings
and outcomes



ISPRM Sydney 2024

Paediatric ME/CFS Clinical Research Program

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Statewide Medical Director, Victorian Paediatric Rehabilitation Service

Royal Children's Hospital, Murdoch Children's Research Institute, University of Melbourne

Dr Elisha Josev MPsych (Clin Neuro), PhD

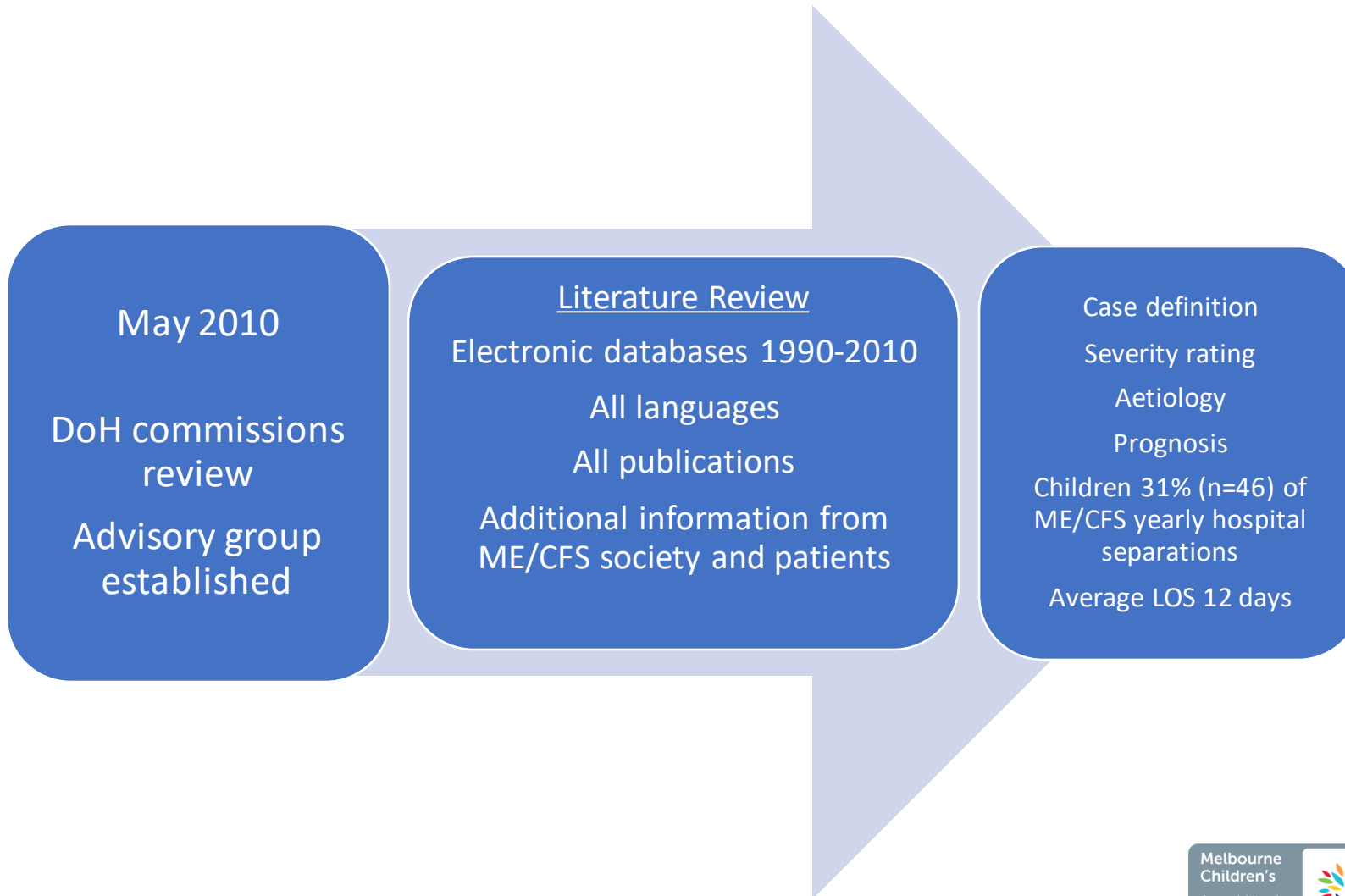
Senior Research Officer, Murdoch Children's Research Institute

Senior Research Fellow, Department of Paediatrics, University of Melbourne

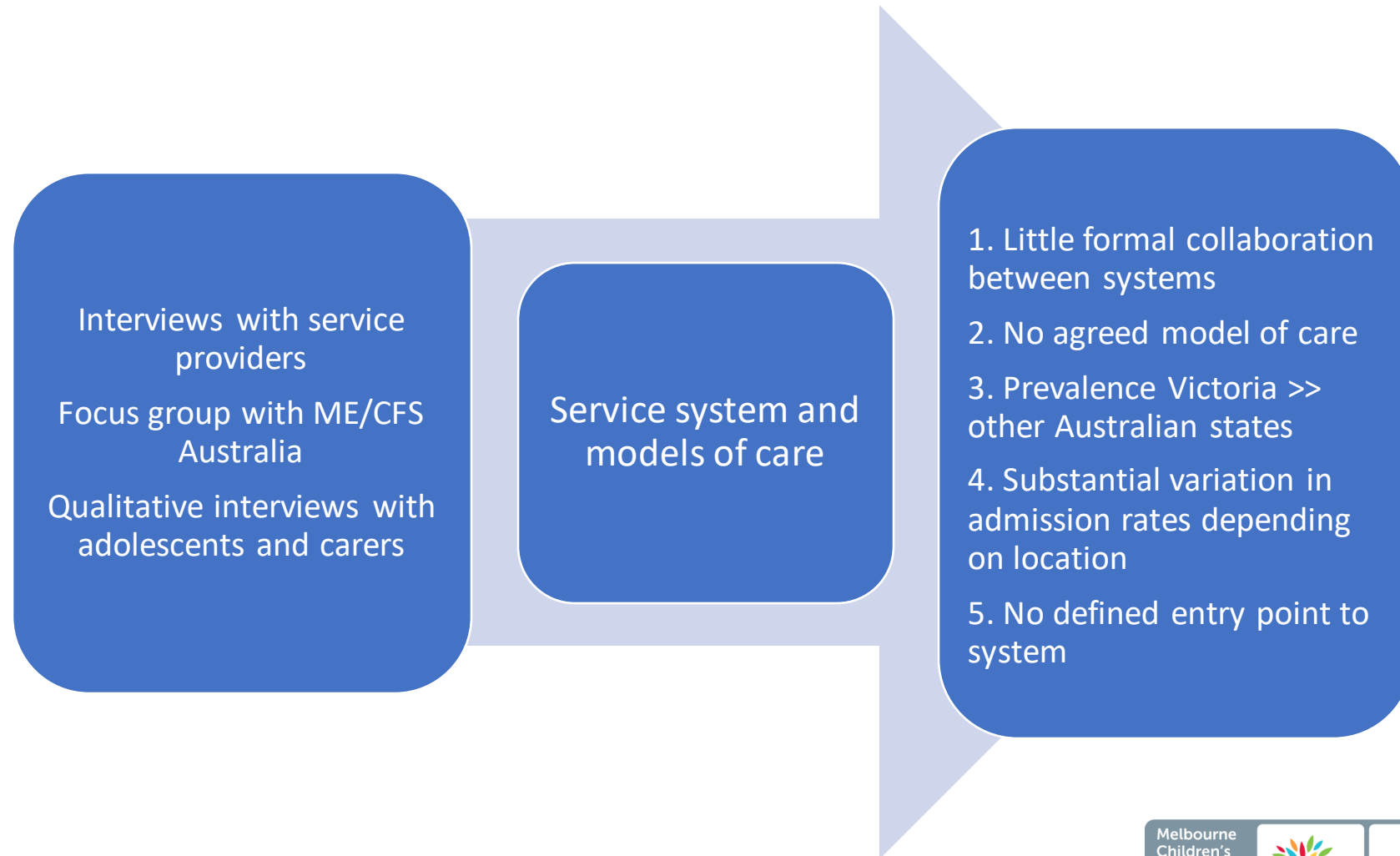
Paediatric Clinical Neuropsychologist, Mercy Hospital for Women



How did we (rehab) get involved in ME/CFS?



Findings of the DHS review



ME/CFS Review – Final Recommendations

- Integrated care across the continuum
- Specialist ME/CFS services with chronic disease model of care
- Access to inpatient and ambulatory rehab at RCH and MCH
- RCH and MCH to develop service ‘identity’, common policy framework, articulated model of care
- Service coordination between ME/CFS services and rehab
- Work towards meeting needs of carers and families
- Increase education of medical, school and community
- Develop a common approach to data collection

Aims of the Paediatric ME/CFS research program

Understand epidemiology of paediatric ME/CFS in Victoria and Australia

Determine current management strategies for children and adolescents with ME/CFS

Determine the evidence base for current practice employed in the ME/CFS population, with a focus on children and adolescents



Understanding epidemiology of paediatric ME/CFS in Victoria and Australia

- International estimates vary (0.0006-2%)
- APSU monthly national surveillance of uncommon conditions
- 71% of all Australian paediatricians report data
- Incidence based on new cases diagnosed over 12 months
- CDC definition
- Estimated national incidence based on 164 cases
- Average age 14.9 years (69% female)
- National incidence 6.4/100,000 (age 10-17 years)
- Victorian incidence 17.5/100,000



Determine current practices

APRN national network of pediatricians established to facilitate multisite secondary care research in Australian pediatric outpatient settings

- 178 Australian paediatricians online survey
- 70 completed CFS module
- Wide variability diagnostic criteria (>50% none!)
- Recommended investigations completed by 17%
- Somatisation, anxiety and depression common
- Sleep, GET and school modification most common Rx

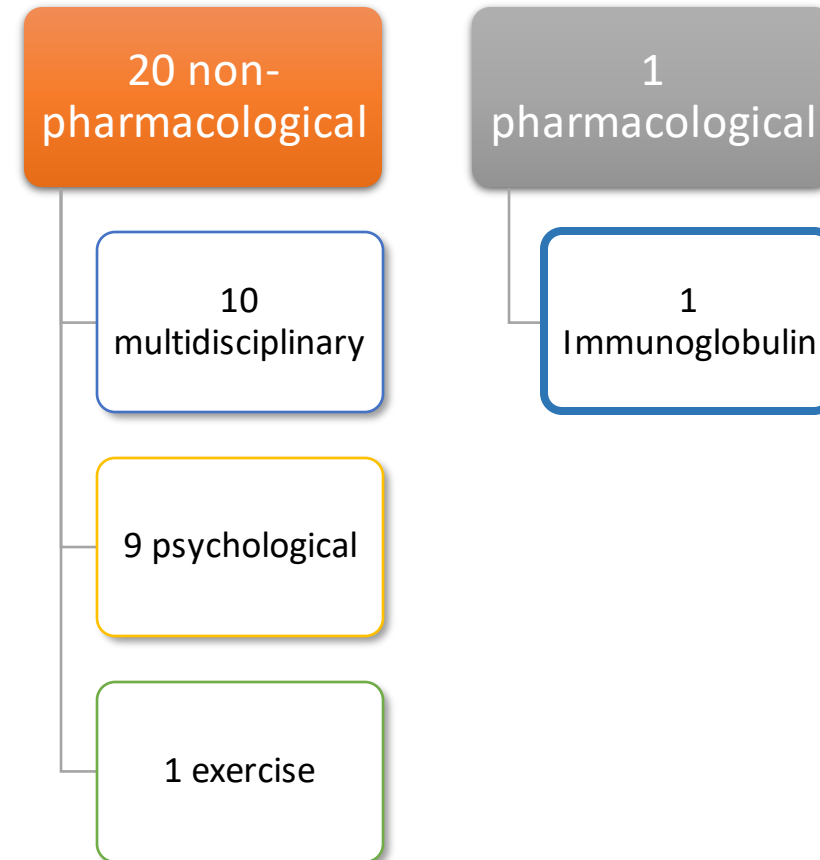
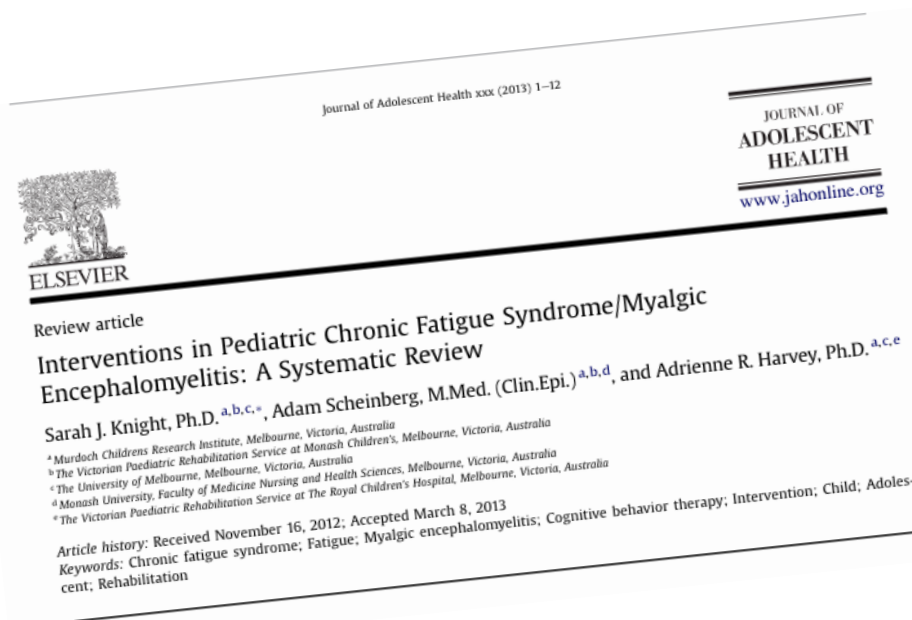
Audit of patients attending CFS clinic RCH over 12 months

- N=99 median time to clinic 15.5 months
- High rates of co-morbid conditions



Determine the evidence base for treatment

- Systematic review
- 24 articles based on 21 studies
- Significant heterogeneity in participants, interventions and outcomes
- Best evidence for CBT then MDT rehab



Outcomes

- Case control study
- Newly diagnosed ME/CFS over 2 years (range 1-5 years)
- Healthy adolescent controls
- N=34 aged 13-18 years
- Fatigue, Sleep, Pain, Depression/Anxiety and HRQoL
- Significant improvement in health and psychological well being
- Fatigue, pain and HRQoL remained significantly poorer
- 65% continued to meet CFS criteria at 2 years



Journal of
Clinical Medicine



Article

Health, Wellbeing, and Prognosis of Australian Adolescents with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS): A Case-Controlled Follow-Up Study

Elisha K. Josev ^{1,2,*}, Rebecca C. Cole ¹, Adam Scheinberg ^{1,2,3,4}, Katherine Rowe ⁵, Lionel Lubitz ⁵ and Sarah J. Knight ^{1,2,4}

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Abstract: Background: The purpose of this study was to follow-up an Australian cohort of adolescents newly-diagnosed with ME/CFS at a tertiary paediatric ME/CFS clinic and healthy controls over a mean period of two years (range 1–5 years) from diagnosis. Objectives were to (a) examine changes over time in health and psychological wellbeing, (b) track ME/CFS symptomatology and fulfillment



Citation: Josev EK, Cole RC, ...

Current and Future Directions of the Paediatric ME/CFS research program



Understanding short- and long-term outcomes of paediatric ME/CFS



Diagnostic biomarkers and underlying pathology of paediatric ME/CFS



Management and treatment of paediatric ME/CFS



Diagnostic biomarkers in paediatric ME/CFS

- Brain biomarkers of neuroinflammation
 - First longitudinal brain study in paediatric ME/CFS using a cognitive exertion paradigm
- Metabolomic and proteomic markers of energy metabolism and mitochondrial dysfunction
 - Deep biochemical profiling at individual level
- Blood biomarkers
 - Australia's first ME/CFS Biobank and Patient Registry

Brain biomarkers of neuroinflammation - Can we map fatigue in the brain?

- 25 ME/CFS, 25 healthy controls aged 13-18 years
- CCC diagnosed by ME/CFS specialist paediatricians at tertiary hospital
- Similar CNS properties/biomarkers
 - Intrinsic functional connectivity
 - Macrostructural and microstructural white matter indices
 - Hypothalamus volumetrics
- Differences in health domains
 - Fatigue, sleep, pain, QoL, cognition

Brain Imaging and Behavior
<https://doi.org/10.1007/s11682-019-00119-2>

ORIGINAL RESEARCH



Resting-state functional connectivity, cognition, and fatigue in response to cognitive exertion: a novel study in adolescents with chronic fatigue syndrome

Elisha K. Josev^{1,2} • Charles B. Malpas^{3,4} • Marc L. Seal^{2,3} • Adam Scheinberg^{1,2,5,6} • Lionel Lubitz^{6,7} • Kathy Rowe^{6,7} • Sarah J. Knight^{1,2,6}

Received: 16 October 2022 | Revised: 28 April 2023 | Accepted: 27 May 2023

DOI: 10.1002/jnr.25223

RESEARCH ARTICLE

JOURNAL OF
Neuroscience Research

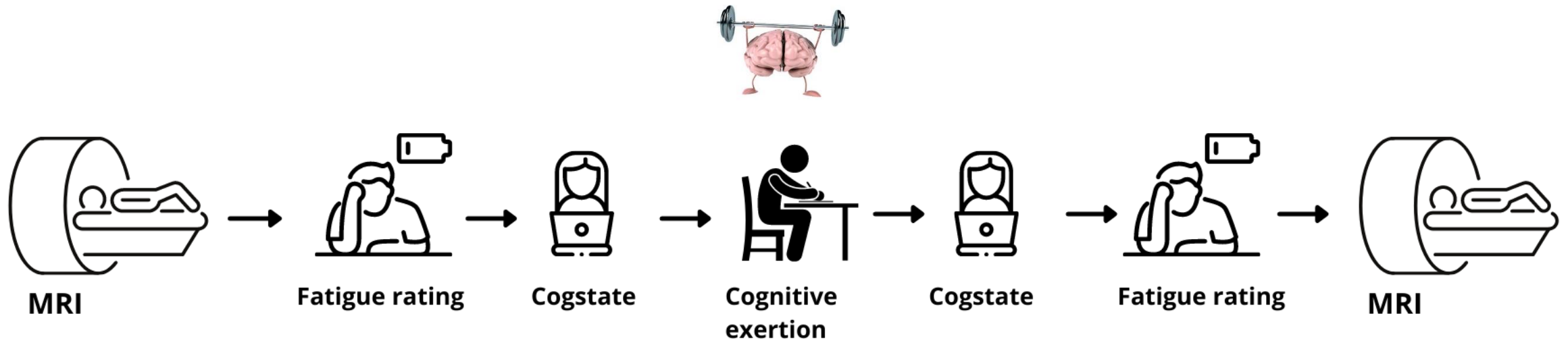
What lies beneath: White matter microstructure in pediatric myalgic encephalomyelitis/chronic fatigue syndrome using diffusion MRI

Elisha K. Josev^{1,2} | Jian Chen³ | Marc Seal^{2,3} | Adam Scheinberg^{1,2,4} |
Rebecca C. Cole¹ | Katherine Rowe⁵ | Lionel Lubitz⁵ | Sarah J. Knight^{1,2,4,6}

Melbourne
Children's
A world leader
in child and
adolescent
health



Cognitive exertion paradigm



T1 T2
Diffusion-weighted MRI
Resting state function MRI
Magnetic Resonance Spectroscopy

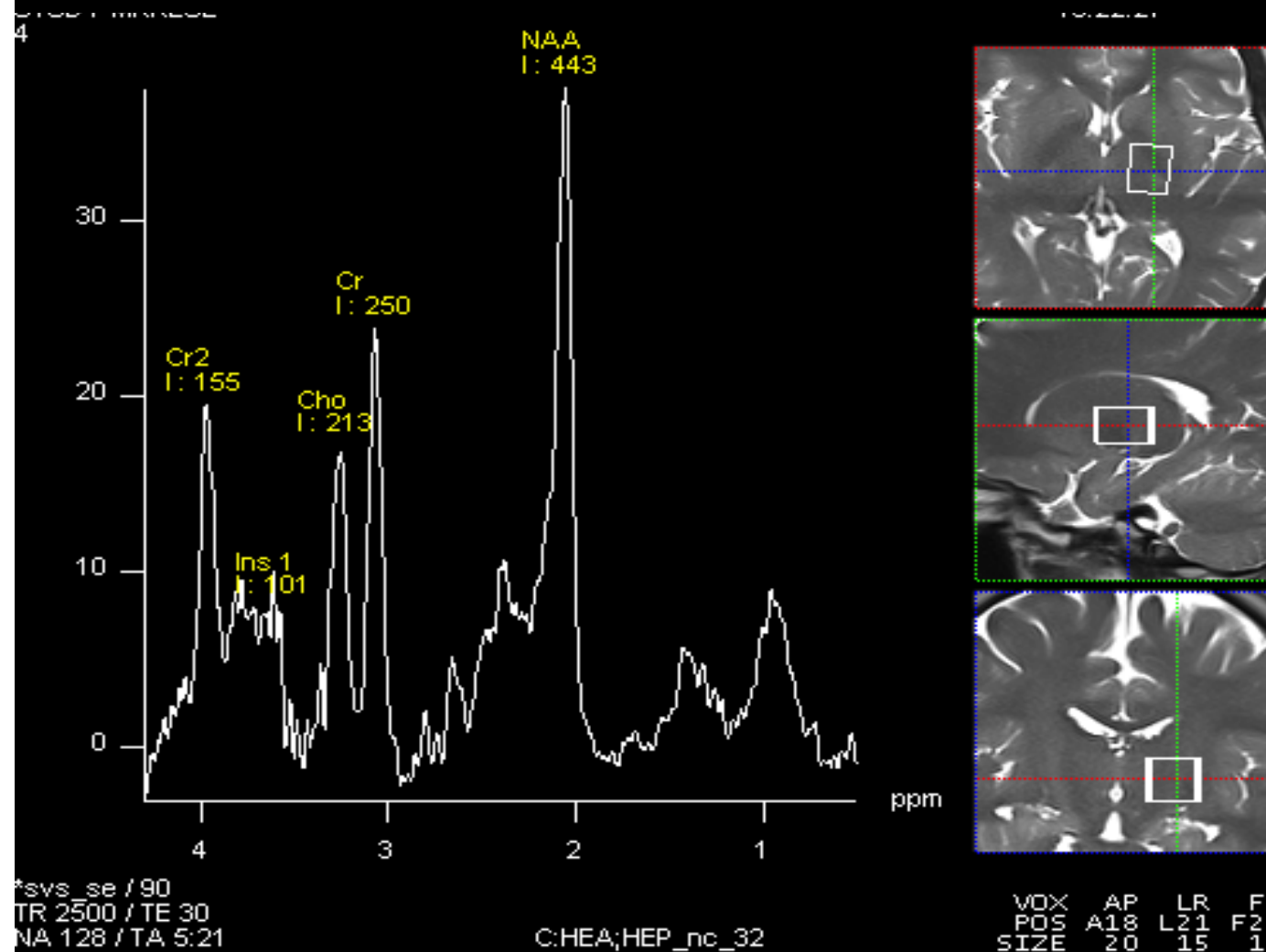
Processing speed
Sustained attention
Working memory
New learning

Word Reading
Numerical Operations
Spelling

Resting state function MRI
Magnetic Resonance Spectroscopy

Magnetic Resonance Spectroscopy (MRS)

The 'virtual biopsy'



Metabolomic and proteomic biomarkers of paediatric ME/CFS (SPOT-ME)



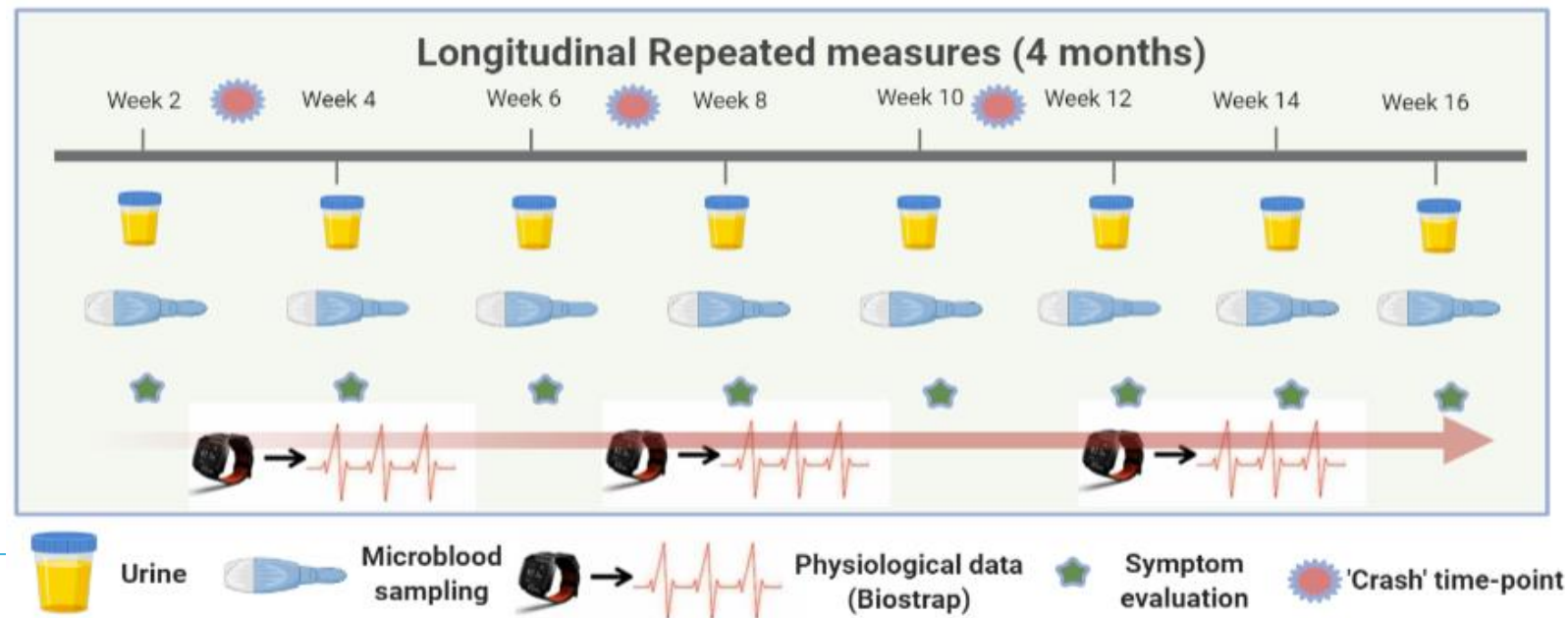
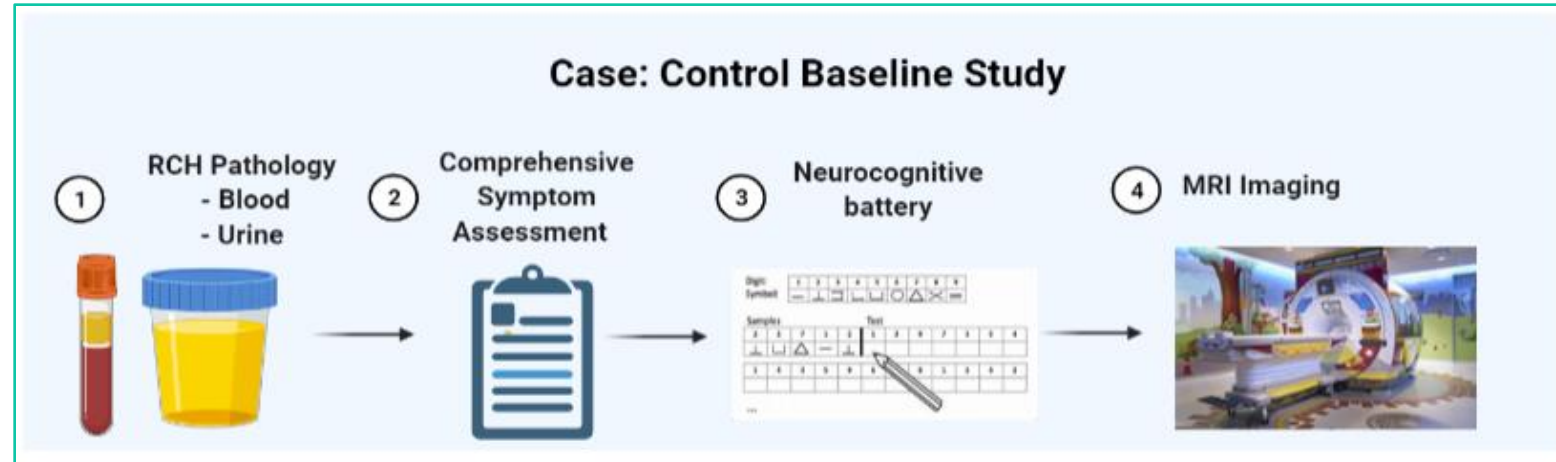
ME/CFS
Outpatients
n= 62



Non ME/CFS
Controls
n= 31



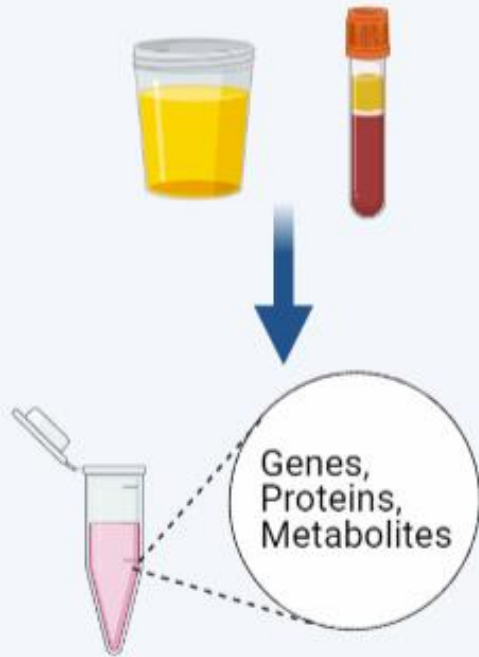
ME/CFS
Outpatients
n= 62



Metabolomic and proteomic biomarkers of paediatric ME/CFS (SPOT-ME)

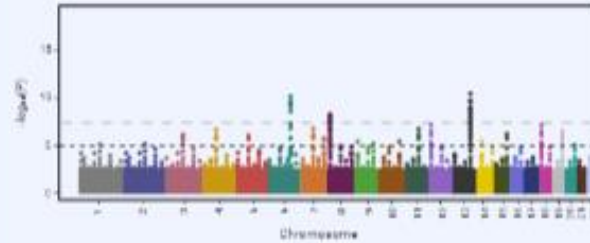
Pre-processing

① Sample processing

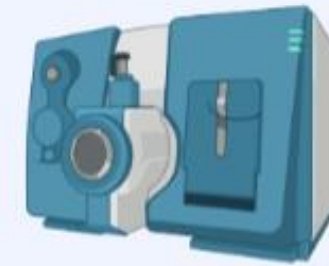


'Deep Dive' Biochemical profiling

① Whole genome Sequencing & Transcriptomics



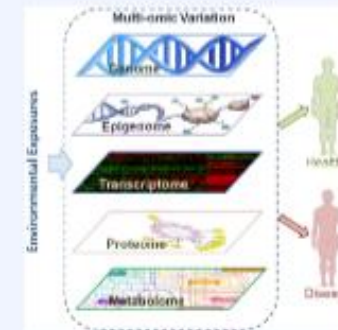
② Proteomics (Mass Spectrometry)



③ Metabolomics (NMR)



④ Multi-omics analysis



Blood biomarkers – Australia's first ME/CFS Biobank and Patient Registry



"Nobody knows the lived experience of ME/CFS better than those who have it, and research can only go so far without your help."

The AusMe Registry is Now Live!

The AusME Registry is open to people with ME/CFS or Long COVID aged 12 and over.

To see more information and sign up, please visit the official AusME Registry website by clicking the link below

[Sign up to AusMe Today! Click Here](#)

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Royal Children's Hospital Medical Imaging Team

Mike Kean



CFS self-
management
course
framework – the
MDT approach



Why focus on self-management?

- Impacts are unique and individual
- Young person is the expert
 - their goals, their dreams, their illness experience
- Aim to empower young people and their families
- Move beyond an impairment model



Why MDT

- ME/CFS affects all aspects of functioning
- Secondary consequences and comorbidities compound symptoms and impairment
- An MDT approach ensures a holistic approach



MDT Approach



Poor sleep – stress/mood/routine - Psychology/OT support



Boom bust activity pattern - impact on ADL's , increasing dependence – OT/ Physio Support



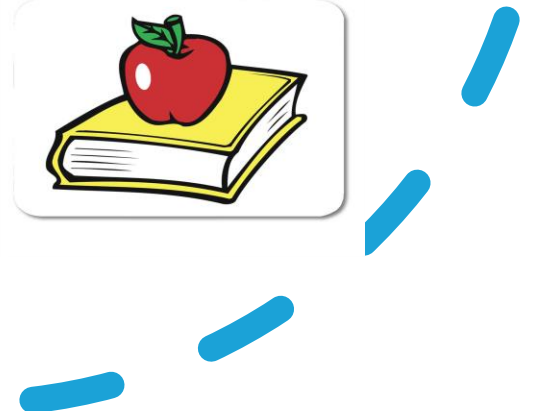
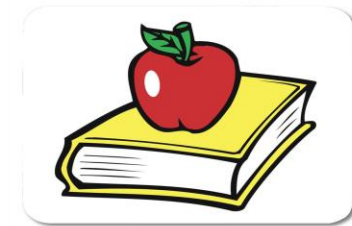
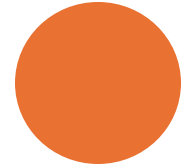
Decreased body movement – pain, energy, orthostatic intolerance , further weakness and pain – Physio support



Decreased appetite - irritable bowel , poor diet – further impact on energy – Dietician support



Mood impact – increased anxiety due to missing school, missing peers , lowered mood, further impacts on energy – Psychology/Teacher support



WHAT HAVE WE LEARNT FROM YOUNG PEOPLE



THEY NEED TO FEEL BELIEVED
AND HEARD



THEY NEED ADVOCACY AND
HELP NAVIGATING EDUCATION
AND CAREER PATHWAYS



THEIR MANAGEMENT NEEDS TO
BE INDIVIDUALISED



THEY NEED TO STAY
CONNECTED

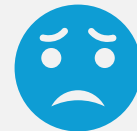
WHAT PARENTS TELL US



KNOWING HOW MUCH TO
PUSH OR NOT IS HARD



THEY WANT TO BE PARENTS
– NOT THE THERAPIST OR
DOCTOR



THEY WORRY A LOT AND IT
IS STRESSFUL

Case Study – 'Cassie'

16 y.o. female referred with likely Chronic Fatigue Syndrome (CFS), presenting with:

- Viral illness 8-months prior, ongoing persistent fatigue since then
- Headaches and dizziness
- Poor sleep pattern, taking a long time to get to sleep at night and regular naps during the day
- Reduced school attendance
- Boom and bust pattern of activity

How could this impact Cassie's life?



Case Study – 'Cassie'

The impact of CFS on Cassie

FUNCTIONING - poor sleep, poor appetite, boom-bust

FUN – unable to hang out with friends on the weekend

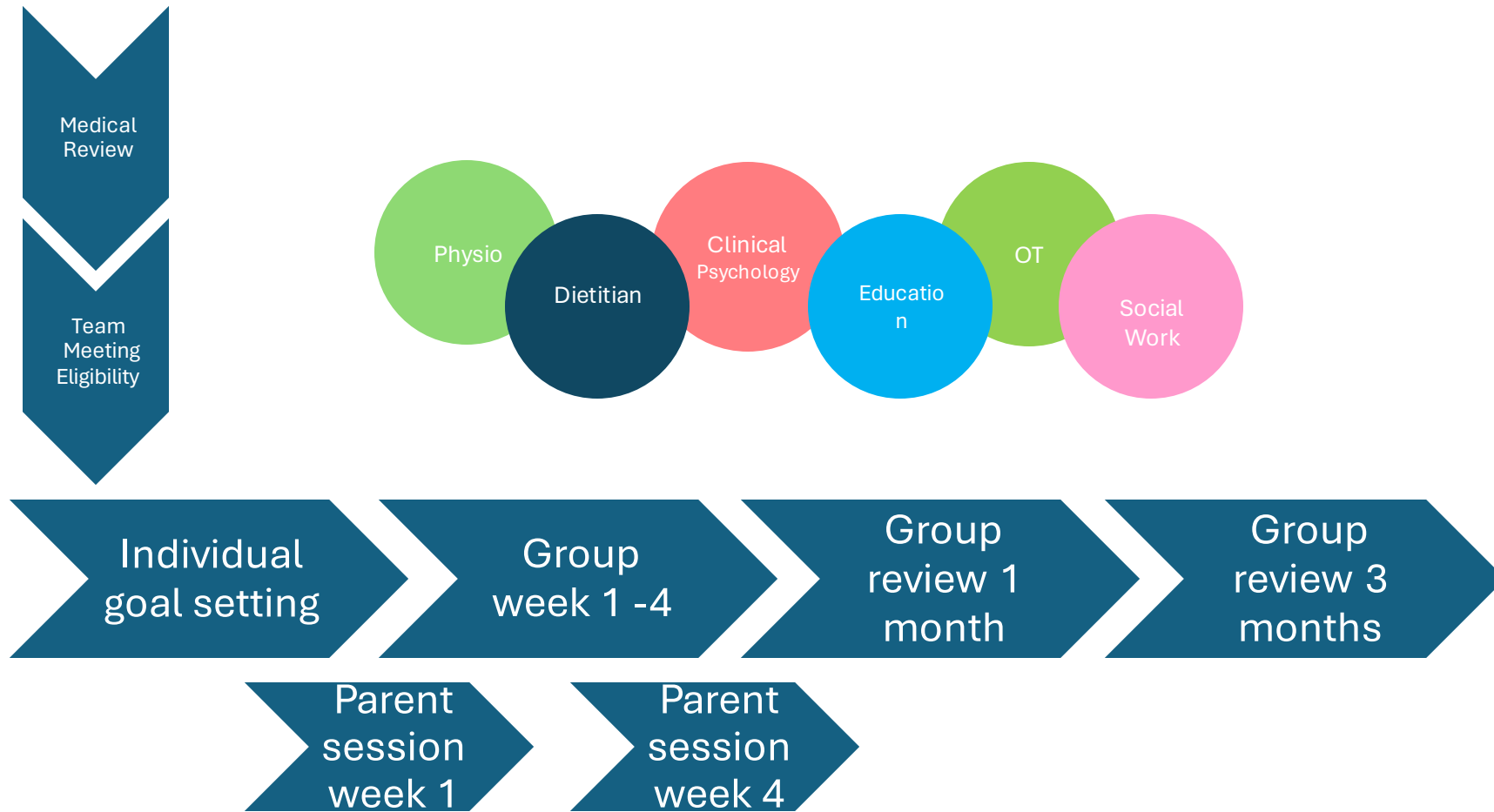
FITNESS – stopped playing soccer

FRIENDS – reduced social contact and resultant social anxiety

FAMILY – poor relationship with siblings due to inability to spend time playing with them.

FUTURE – reduced school attendance impacting academic achievement, lowered mood impacting vision for future.

CFS Program



Participants:



Inclusion	Exclusion
Confirmed CFS diagnosis	Significant mental health concerns
Self-Identify goals/attitude for change	Unwilling to participate in a group
Aged 12-19 years	
Attending school at least 2 days a week	
Minimum continuous walking tolerance 15 minutes	
Has a general daily routine/ sleep wake cycle that enables attending the group - but may continue to boom and bust	
English speaking	

MANAGEMENT AIMS



1.TO MAINTAIN
FUNCTION AND
MINIMISE SYMPTOMS
REBOUND

Graded
activity/pacing
Avoid boom bust
activity pattern



2.TO
PREVENT/MANAGE
SECONDARY
CONSEQUENCE

Deconditioning
Social isolation
Halt in education
pathway
Anxiety and
lowered mood



3.TO ENABLE THE YOUNG PERSON TO
ACHIEVE THEIR GOALS

Anxiety



Consumes energy, has secondary physical consequences , ...so very fatiguing in and of itself



Can exacerbate POTS symptoms (even mild levels)

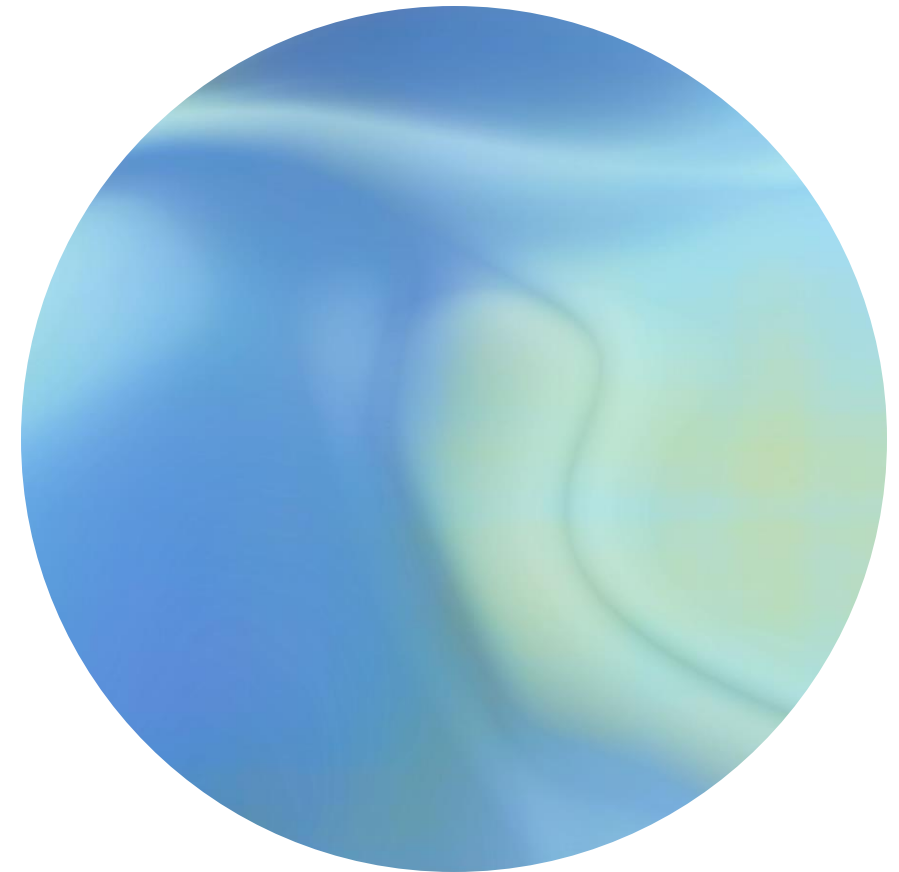


Can worsen CFS symptoms (limited bucket of energy expended on anxiety/worry/stress response)



Mx- Good evidence for CBT approach

Can engage in management by explanation of physical impacts of anxiety on body and on fatigue/energy



Outcomes Measures

Primary outcome measure:

- Canadian Occupational Performance Measure (COPM)

Secondary outcome measures:

- Sit to stand test
- Crash days per week
- Dynamometer
- PedsQL Multidimensional Fatigue Scale
- Strengths and difficulties questionnaire

Self-management program outcomes 2021-2023:



16 PARTICIPANTS



9 COMPLETED FULL
PROGRAM, 7 LOST TO
FOLLOW UP AT 3MONTHS



MEAN CHANGE IN
PERFORMANCE = 4.5



MEAN CHANGE IN
SATISFACTION = 4.1



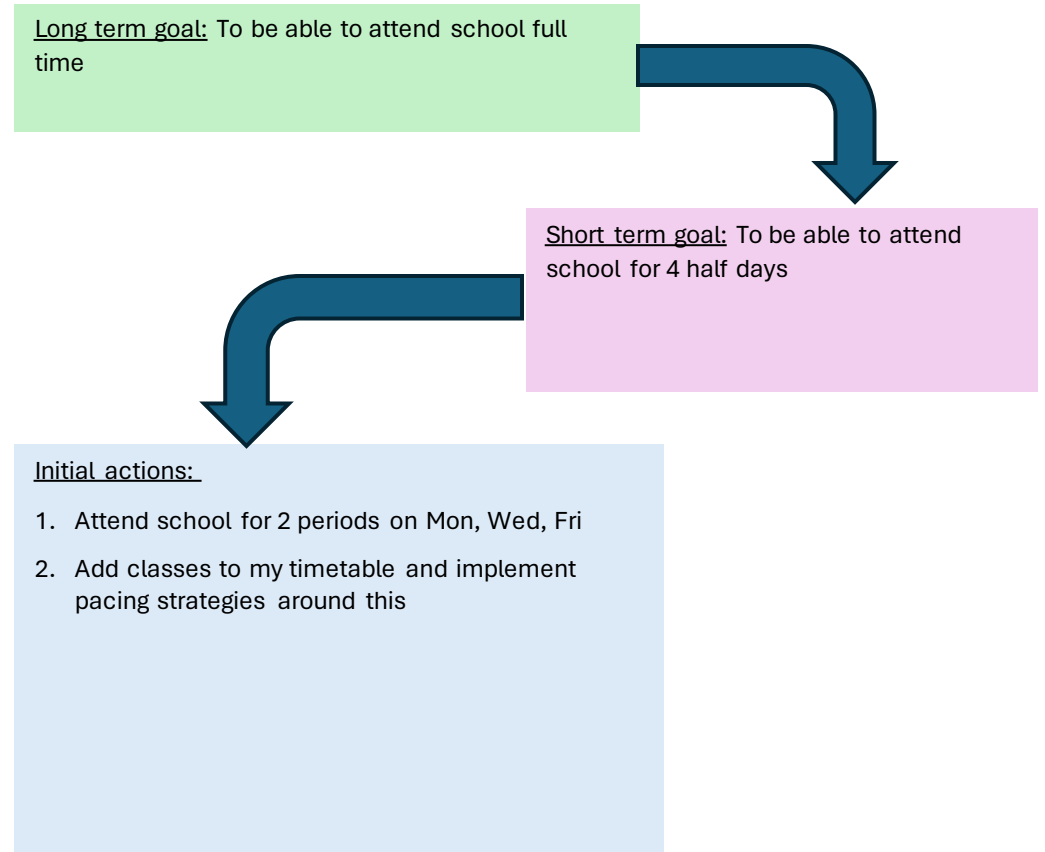
THIS IS CLINICALLY
SIGNIFICANT CHANGE

Goal setting for
young people
with CFS & How
to manage
energy – the
traffic light
system



Goal setting

- Goal setting is used to individualise the program to each young person
- Use of the Canadian Occupational Performance Measure (COPM) to set functional, SMART goals and to use this as an outcome measure
- Goal setting helps build motivation and helps them breakdown the goal to help it feel more achievable
- NICE guidelines support meaningful goal setting to help young people establish realistic expectations



Case Study – 'Cassie'

Goals:

1. To return to playing soccer
2. To be able to return to full time school
3. To be able to get to sleep within 30-minutes, and not nap during the day
4. To be able to hang out with friends on the weekend once every fortnight

Case Study – 'Cassie'

Goal 1: To return to playing soccer

Short-term goal: To be able to complete a modified training session

Actions to achieve goal:

1. Commence graded exercise program
2. Timetable exercise into activity planner

Goal 2: To return to school full time

Short-term goal: To be able to attend school for 4 half days each week

Actions to achieve goal:

1. Grade back to attend 2 periods on Mon, Wed, Fri
2. Add classes into my activity planner and implement pacing strategies

Goal 3: To be able to get to sleep within 30minutes and not nap during the day

Short-term goal: To be able to get to sleep within 1 hour and only nap for 30minutes twice a week

Actions to achieve goal:

1. Develop good sleep hygiene – no technology 1 hour before bed, mindfulness activity for 20minutes, keep consistent bed times
2. Schedule into activity planner days that will have a nap, set an alarm for 30minutes when start to nap

Goal 4: To be able to hang out with friends every fortnight

Short-term goal: To be able to do a social activity with a friend once a month

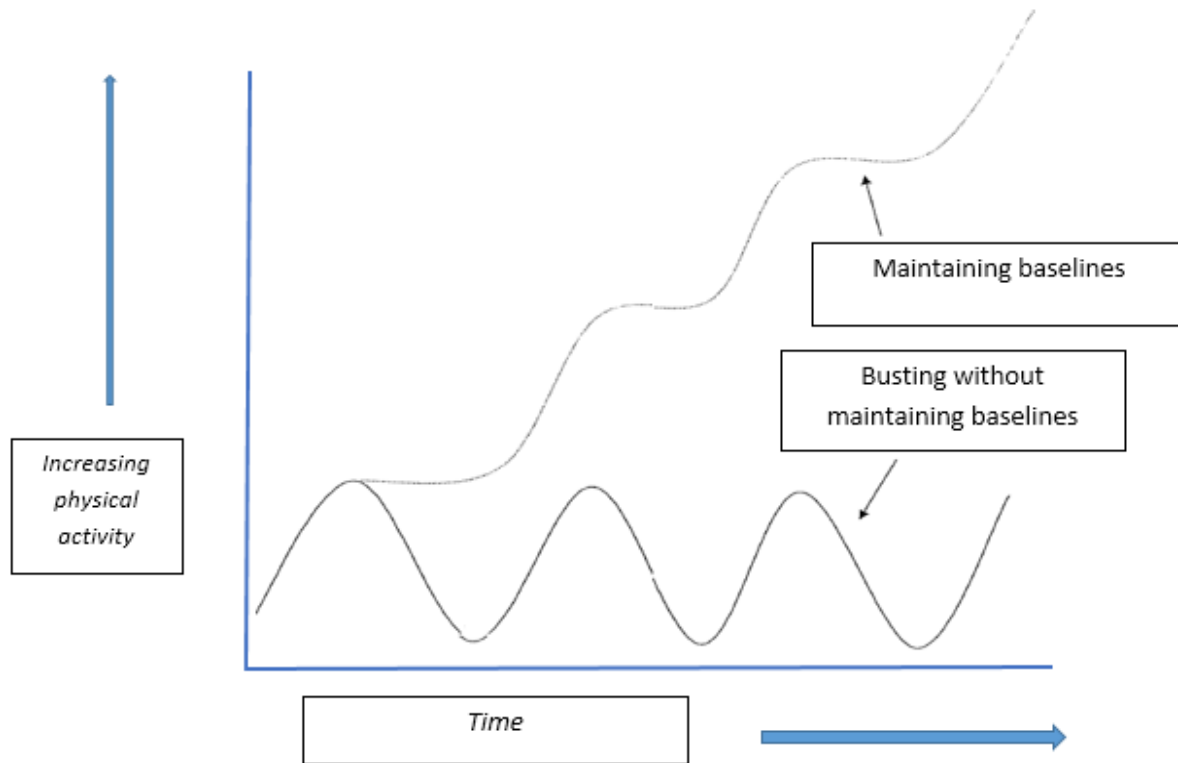
Actions to achieve goal:

1. Schedule into activity planner so can pace activities around this event
2. Slowly build up from baseline by sticking to consistent routine, so have more energy in my battery

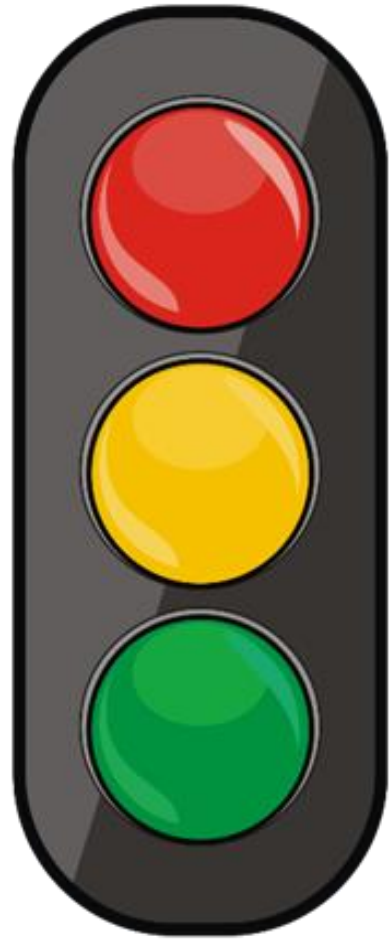
How do we teach young people with CFS to manage their energy and work towards achieving their goals?



Baseline



- Importance of establishing a consistent baseline, as this gives us a starting point to gradually increase from.
- Important to work towards avoiding boom and bust cycle and building consistency



Red = high energy
consumption activity

Yellow = moderate energy
consumption activity

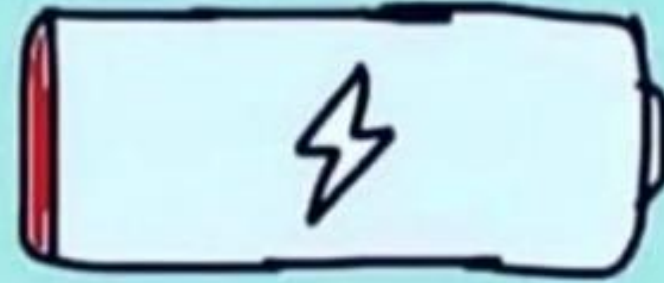
Green = low energy
consumption activity

Traffic light system for pacing

- Visual representation of energy expenditure throughout the week
- Helps pacing out activities
- Use to forward plan but can assist reflecting after
- Encouraged to use strictly in a calendar/activity planner initially to help with finding baseline and balancing activities.

Energy conservation and Pacing

- Breaking up longer tasks into smaller chunks with rest breaks in between
- Adapting/modifying tasks to reduce energy consumption
- Using a diary or activity planner
- Spreading out big activities so not all on one day



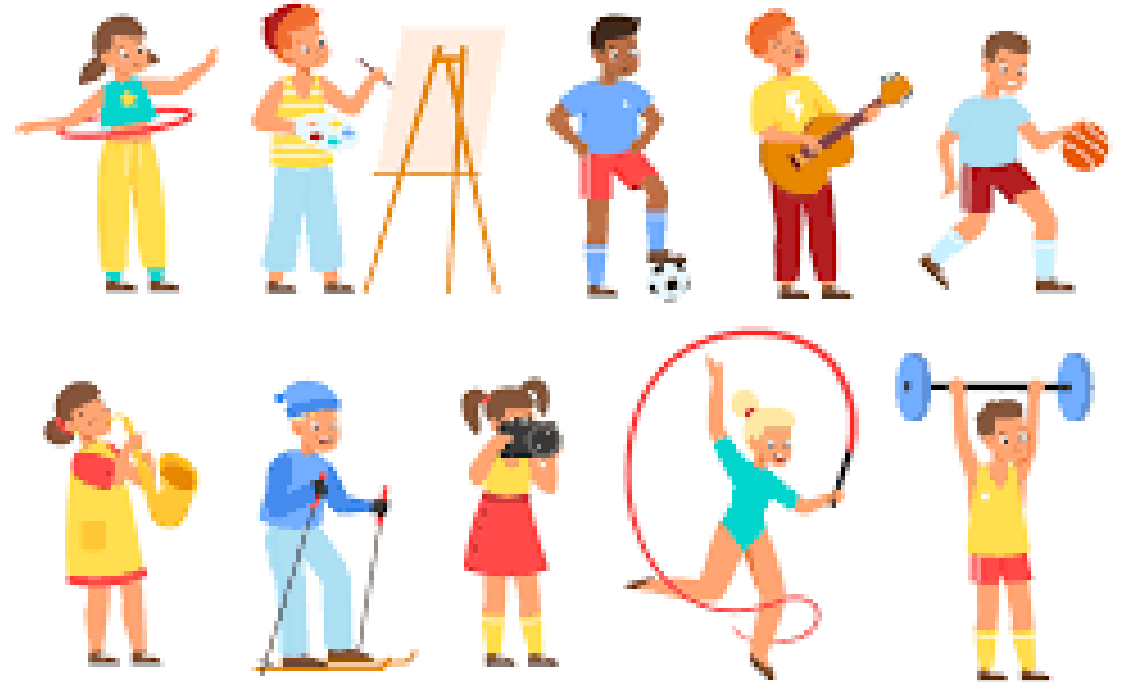
**YOU WOULDN'T LET THIS
HAPPEN TO YOUR PHONE.
DON'T LET IT HAPPEN TO
YOU EITHER.**

Case Study – 'Cassie'

Activity planner example:

Time	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
7 am	7:30 alarm 7:45 out of bed	7:30 alarm 7:45 out of bed	Sleep	7:30 alarm 7:45 out of bed	7:30 alarm 7:45 out of bed	Sleep	Sleep
8 am	Breakfast and self-care – ready for school	Breakfast and self-care – ready for school	8:30 alarm 8:45 out of bed	Breakfast and self-care – ready for school	Breakfast and self-care – ready for school	8:30 alarm 8:45 out of bed Breakfast and self-care, relax on couch	8:30 alarm 8:45 out of bed Breakfast and self-care, relax on couch
9 am	Math	Food technology	Breakfast and self-care – ready for school	Health	P.E		
10am	English	Food technology	Independent learning at home	Psychology	P.E	Study – 2x 30mins with 5min rest	Study – 2x 30mins with 5min rest
11am	Science	English	Rest on couch	Math	Art	Walk dog	Walk dog
12.00	Lunch at school	Lunch at school	Lunch at home	Lunch at school	Lunch at school	Lunch and Quiet activity	Lunch and Watch TV
1 pm	Art	Health	Independent learning at home	Travel home from school, snack	Math	Watch soccer team play	Watch TV
2 pm	Travel home from school, snack	Psychology	Independent learning at home	Soccer skills program at home	History	Nap	Kick soccer ball with sibling
3 pm	Revising schoolwork	Travel home from school, snack	Reading in bed	Relax on couch and time with family	Travel home from school, snack	Quiet activity	Study – 2x 30mins with 5min rest
4 pm	Relax on couch and time with family	Relax on couch and time with family	Relax on couch and time with family	Computer games with friends	Walk dog with a friend	Shower and get ready	Drawing
5 pm	Study – 2x 30mins with 5min rest	Soccer training	Phone/computer time - games and socialising with friends	Study – 2x 30mins with 5min rest	Quiet activity	Rest – Reading in bed	Phone/computer time - games and socialising with friends
6 pm	Dinner and time with family	Dinner and time with family	Dinner and time with family	Dinner and time with family	Dinner and time with family	Dinner and hang out with friends	Dinner and time with family
7 pm	Shower	Shower	Shower	Shower	Shower		Shower
8 pm	Start to get ready for bed	Start to get ready for bed	Start to get ready for bed	Start to get ready for bed	Start to get ready for bed		Start to get ready for bed
9 pm	Get into bed 9:30 - sleep	Get into bed 9:30 - sleep	Get into bed 9:30 - sleep	Get into bed 9:30 - sleep	Get into bed - 10 10:30 - sleep	Get into bed - 10 10:30 - sleep	Get into bed 9:30 - sleep

How to help
achieve activity/
participation
goals & what
about parents and
carers?



Exercise

- Gradual return to exercise (i.e. Graded Exercise Therapy)
- Consideration of intensity vs. duration continuum
- Mix of cardiovascular and resistance-based exercises
- Stop the “losing part” of the “use it or lose it” principle



Principles of graded exercise

Phase 1

- **Short burst intervals**
- *Level 1:* 2 x 2 minute bursts with 3 minute recovery
- *Level 2:* 3 x 2 minute bursts with 3 minute recovery
- *Level 3:* 5 x 2 minute bursts, gradually reducing the recovery time to 1 minute

Phase 2

- **Lengthen the bursts**
- *Level 4:* Progress to 2 x 5 minute bursts with a 3 minute recovery, gradually reducing the recovery time to 1 minute

Phase 3

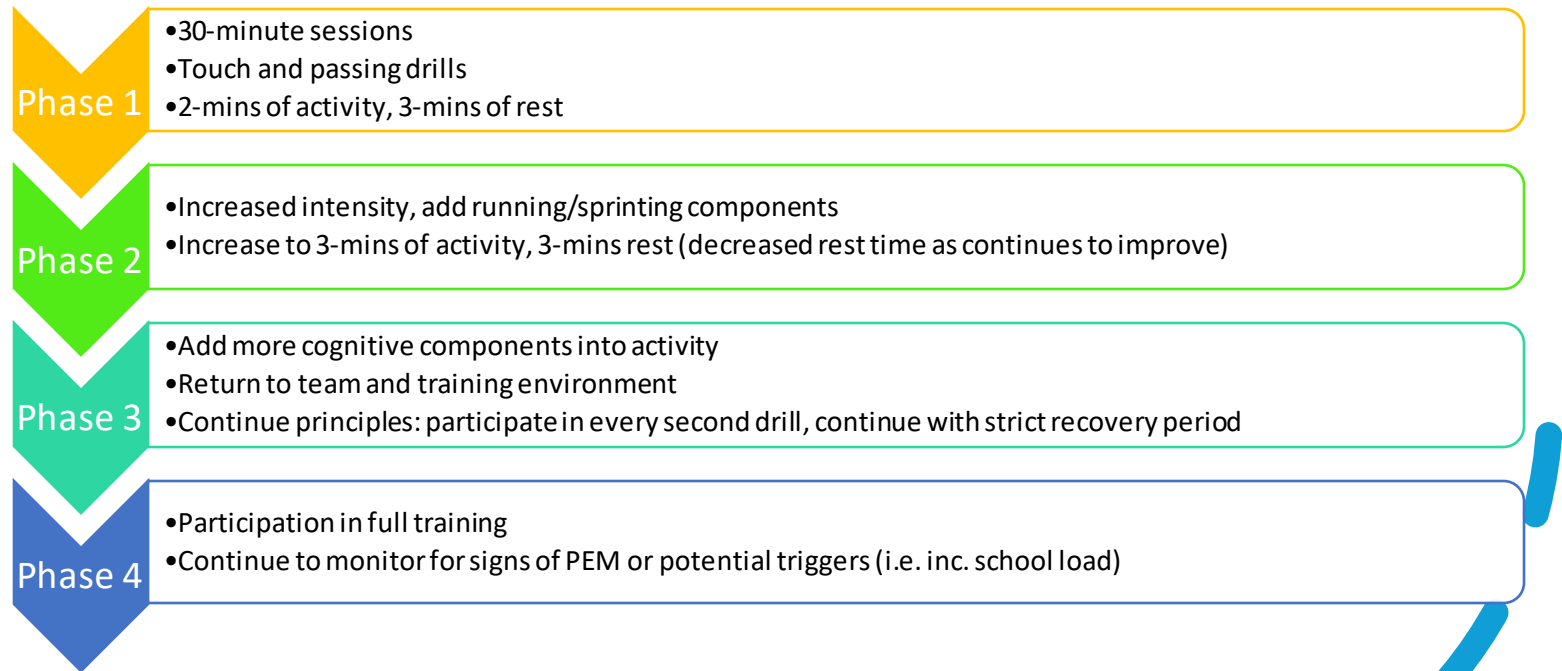
- **Continuous walking/riding/cross trainer**
- *Level 5:* Start at 10 minutes and only increase by 1 minute every couple of days

Phase 4

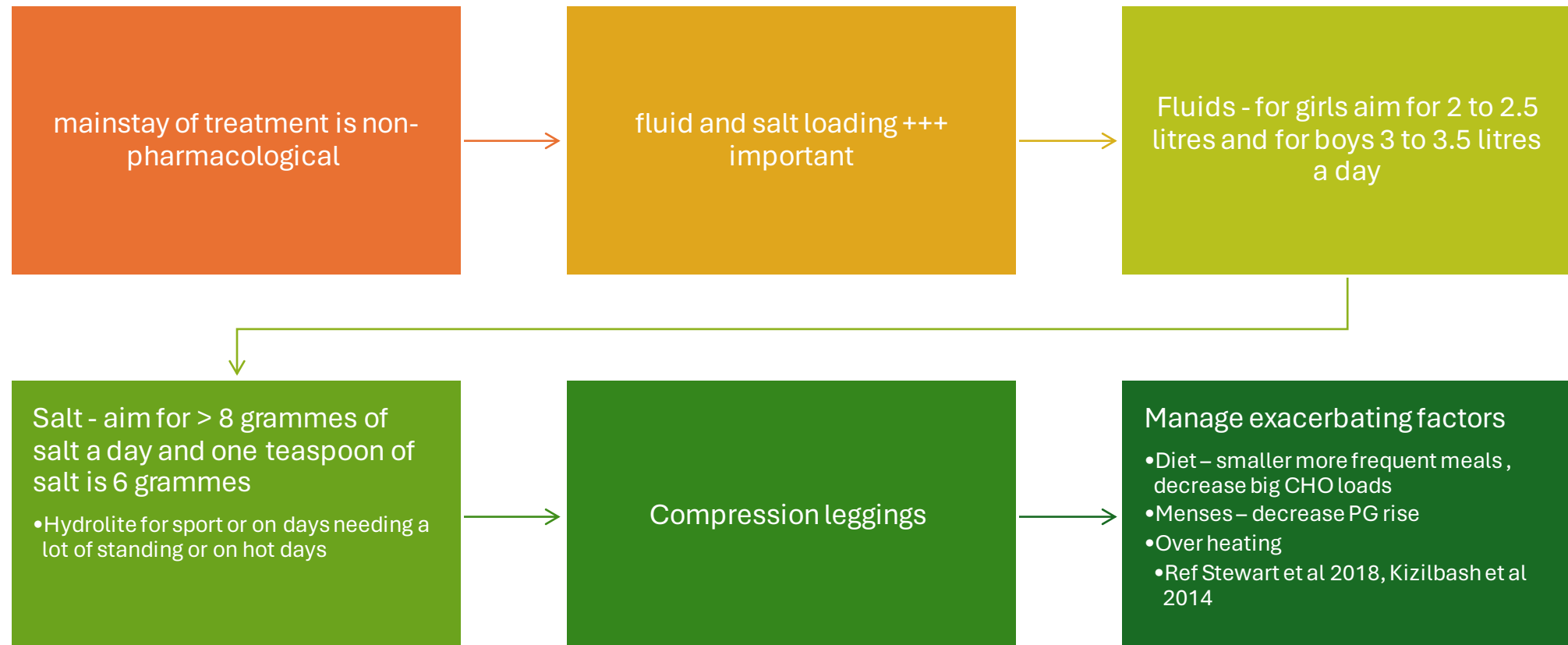
- **Increase intensity**
- *Level 7:* Now you can increase the intensity of the exercise to 'somewhat hard' (i.e. 13 on the Borg scale). This should be done very gradually (i.e. increase the intensity for 1 minute in every 5 by increasing your pace or resistance or walking up hill/adding in stairs). Only increase at a maximum rate of once per week.

Case Study – 'Cassie'

- Wanted to consider a return to soccer
- Discussed a “pre-pre-season” approach
- Applied principles of graded exercises in a soccer context



OI/POTS Mx



How to advocate in the education setting



EDUCATION AND HEALTH CARE PARTNERING TO ASSIST YOUNG PEOPLE

Monash Children's Hospital School (MCHS) is a Department of Education (DET) school located within Monash Children's Hospital (MCH). The school has been established to provide education for children who are inpatients and/or outpatients of Monash Children's Hospital



SCHOOL IMPACTS

Impact on school functioning:

Study by Knight et al in Victoria in 2018 found

- Adolescents with CFS missed on average 40% of a school term
- Greater severity of fatigue in adolescents with CFS was associated with
 - lower levels of school attendance,
 - Lower quality of life in the school setting,
 - Lower participation and connectedness
- This negatively impacts
 - Academic competence
 - Social competence
- Another long term outcome study noted 1 academic year was the mean time out of school - Rangel et al 2000



“School is the principle location for the development of not only academic skills, but also cognitive, social, and community-related skills during childhood and adolescence”

Knight et al



EDUCATION SUPPORT FOR YOUNG PEOPLE DIAGNOSED WITH CFS



GATHER HISTORY

Gather information
from parents &
young person

SYMPTOMS

Brain fog – struggling with concentration

ATTENDANCE

Struggle to get to school → Get to school late
→ Not attending at all

ACADEMICS

Keeping up with work → Doing some work at home → Not completing any work

SOCIAL CONNECTIONS

Connected to friends – see them at school & socially
Some connections with friends – mainly on social media

Attend the appointment with the Paediatrician



DEVELOP A PLAN

ATTENDANCE

Reduce time at school → Reduce number of days

ACADEMICS

**Subject load – focus on core subjects →
Prioritise the work to complete at home & / or
School**

**SOCIAL
CONNECTIONS**

**Encourage young person to reach out to
friends**

**SCHOOL
SUPPORTS**

**Identify the best contact at the school
Encourage connection to Wellbeing team
Break card and quiet space to rest & recharge**

CFS SUPPORT PLAN

STUDENT DETAILS:		DATE OF COMPLETION:		12 / 2023
Name:	ALICE BARTLET		Year Level:	YEAR 11
STUDENT SUPPORT PLAN				
PURPOSE OF PLAN:				
The aim of the plan is to support Alison to engage with her education and support a gradual increase in expectations to reduce the likelihood of a fatigue crash				
SUPPORT STRATEGIES				
<ul style="list-style-type: none"> Reset breaks — stand up, stretch, get a drink Rest breaks — head to health centre for rest Fidget toys & Loop headphones — help manage stress and noise in class room 				
PEOPLE WHOM I CAN ASK FOR HELP		PLACES I CAN GO WITHIN THE SCHOOL		
Head of House School Nurse		Health Centre Head of House - office		
STUDENT ACTION PLAN				
<ol style="list-style-type: none"> Break up class periods with reset breaks Use free periods for late start, early finish & rest periods Attempt to spend recess / lunch break outside Use sticky notes on laptop to record homework / important dates Take screen shots of notes to reduce note taking Speak up when fatiguing rather than push through 				
REVIEW DATE				
This plan will be reviewed on:				
SIGNATURES:				
Student Signature				
Parent Signature				
School Support Person Signature				

Week A	Monday	Tuesday	Wednesday	Thursday	Friday
FA	Form Assembly	Form Assembly	Form Assembly	Form Assembly	Form Assembly
Period 1 (9.04-10.14am)		English	Fashion Product Design	English	Maths
Period 2 (10.17-11.27am)		Maths			Fashion Product Design
Period 3 (11:50-1:00pm)				Maths	English
Period 4 (1.48-2:58pm)	Maths				

Week B	Monday	Tuesday	Wednesday	Thursday	Friday
FA	Form Assembly	Form Assembly	Form Assembly	Form Assembly	Form Assembly
Period 1 (9.04-10.14am)			English		
Period 2 (10.17-11.27am)		Maths		English	
Period 3 (11:50-1:00pm)	Maths			Fashion Product Design	
Period 4 (1.48-2:58pm)	Fashion Product Design	English		Maths	English

**HAMISH LITTLE
(YR 6)**

EXIT PASS

This card is used to excuse
Hamish Little (YR 6) from class
as he is not feeling well.

Hamish needs to make his way
directly to the office.



CONTACT SCHOOL

Gather information
from school that may
be useful to the
medical team

CALL

Speak to the identified contact → Discuss
and advocate for the plan → Answer
questions

Identify if there have been challenges at
school – with academics, peers and what
attendance has been like

EMAIL

Send follow up email → Copies of useful
documents - Fact sheet
Modified timetable, Modified Learning Plan
&
Contact details for further communication

ABSENCE LEARNING PLAN

NAME:

YEAR LEVEL:

DATE:

REVIEW DATE:

KEY CONTACTS:

CONTACT DETAILS:

SCHOOL:

MONASH HEALTH:

HOME:

PURPOSE OF PLAN:

The aim of the plan is to allow **NAME** to engage fully with her recovery

To facilitate this our school plan is focussed on:

- Minimising workload, deadlines and assessments as much as possible
- Ensuring key knowledge and skills are acquired within a reduced workload

Supporting her pathway to complete

SUBJECT:	SUBJECT:	SUBJECT:	SUBJECT:
TEACHER:	TEACHER:	TEACHER:	TEACHER:
EMAIL:	EMAIL:	EMAIL:	EMAIL:
LEARNING TASKS:	LEARNING TASKS	LEARNING TASKS:	LEARNING TASKS
ADDITIONAL INFORMATION:			
IMPORTANT DATES:			

Physics

In Term 2 we'll be continuing with motion in 10PHY:

Motion

- Distance, displacement, speed, velocity and acceleration-definitions and formulae
- Vector quantities

Motion – distance/time and speed/time graphs.

Commerce

Will have now started Accounting in Co 101s. When **Will** returns in Term 2 the class will be continuing with the Accounting equation (folio exercises) and preparing for the CAT (Accounting Test)

Will has access to all our materials via our/his ONE NOTE pages if he wants to participate. He is welcome to complete the CAT (Accounting Test)

If he finds it overwhelming, then he can complete the Investment classes task (HAMAL'S LIFE Case Study) of which I can use as his Summative (CAT) result.

Week 8	Accounting	The Accounting Equation and Elements (Assets, Liabilities, Owners Equity) Balance Sheet Meaning from balance sheet – Gearing and Liquidity (very basic) Two fold effect on Balance Sheet (basic transactions).	
Week 9	Accounting	Continue week 8 content Basic intro to Princs and Characteristics (only Entity and reporting period assumption and Qualitative characteristic of Verifiability)	Folio of exercises
Week 10	Accounting	Introduction to risk and reward -investments: Property market, share market and cash investments. Key Idea: Explain why and describe how people manage financial risks and rewards in the current Australian and global financial landscape	

Helping Students Who Have Chronic Fatigue Syndrome

When teaching adolescents or younger children with CFS, it can be helpful to understand the problems faced by these students. A key to helping students with CFS is to work as a team with their teachers, parents, administrators, other education professionals, and healthcare professionals. This team approach can provide flexibility with educational plans and school resources that are customized to target and reflect the student's needs.



CFS affects each student differently is a complex illness affecting the brain and immune system. It is characterised by neurological, gastrointestinal and musculoskeletal symptoms, pain and disabling fatigue. It is a chronic disease which can result in major disruption to educational, social, physical and emotional development for many months or years. Each child may experience different symptoms and the duration of their symptoms may differ as well. Symptoms can fluctuate from day to day and week to week, affecting a young person's ability to attend school regularly and perform consistently.

CFS can affect children and adolescents in many ways, including their:

- Attendance
- Ability to participate both inside and outside of the classroom
- Relationships with peers
- Ability to complete work and
- Overall school success

Understand How CFS Affects Students Inside and Outside the Classroom

Students with CFS are often very keen to return to school but become easily exhausted. Because children differ so much in the severity and range of their symptoms, it is important to discuss individual cases with parents. By doing so, schools will be able to utilise a student's strengths and be aware of his or her particular situation.

- School performance or attendance can be affected by a student's CFS symptoms, such as memory or concentration problems, unrefreshing sleep, and headaches.
- Adolescents and younger children with CFS can experience problems when trying to do several things at once—for example, doing their homework and keeping track of time; understanding and flexibility are essential.
- Many children with CFS experience more severe symptoms in the morning hours and may have trouble getting to school on time or staying alert in the morning at school.

- Children with CFS can have problems with attention, response time, information processing speed, and delayed recall of verbal and visual information.
- Teachers may notice that students with symptoms mentioned above may be able to complete grade-level tasks, but might require more time to do so.

Tips for Teachers and Coordinators

Because CFS is a complex disorder that affects how students learn and participate in school, teachers and Coordinators may want to be creative in developing strategies to foster an encouraging learning environment for their students with CFS. Schools can assist students with CFS in the following ways:

- clarify essential learning tasks and give clear boundaries about which tasks need not be done;
- arrange for missed work, notes, school newsletters and so on, to be made available for easy collection (e.g. a folder in the front office);
- tape important lessons;
- make educational videos or audiotapes available;
- ensure that all staff are aware of student's limitations, particularly in relation to exercise and sport, and the need for rest;
- minimise administrative requirements (e.g. presenting notes for being late);
- trust the student to know his or her limitations -discuss any concerns with parents;
- provision of quiet, well-ventilated rest area, ideally separate from infected students in sick-bay area;
- recognise difficulties with mobility presented by widely-spaced school facilities, stairs, etc.

*NOTE: The list above is not exhaustive. Teachers and Coordinators may need to explore other strategies to accommodate the particular needs of each individual student with CFS.

Information sourced from:
Dr Sabine Hoppel, VPRS MCH
<http://www.ahmf.org/education.html>
<http://www.chronicillness.org.au/>
<http://www.cdc.gov/nce-cfs>

REVIEW PLAN

Set a goal – create an individual support plan

ATTENDANCE

Review current plan
Stay the same → Increase

ACADEMICS

Review subject load & Learning
Support Engaged
VCE – other supports available

SCHOOL
SUPPORTS

Update school & discuss other supports
Break card and quiet space to rest &

SOCIAL
CONNECTIONS

Encourage young person to reach out to
friends & spend time with friends

Individual Support Plan (ISP)

NAME: _____

SCHOOL: _____

YEAR: 11

DATE: _____ REVIEW DATE: _____

ASSESSMENT

SCHOOL INFO

YEAR 11

English
Maths Methods
Business Management
Economics
Accounting
Religion & Society

GOAL

1. Select subject to remove by end of week 2.
2. Implement CFS Management plan.

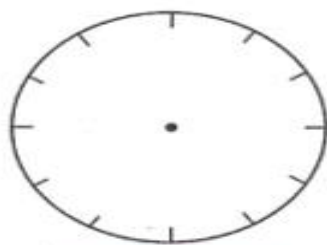
PLAN

STUDENT

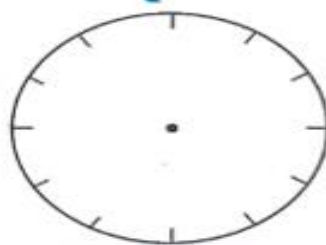
- inform school which subject to remove
- use CFS plan to reduce/monitor fatigue

SCHOOL

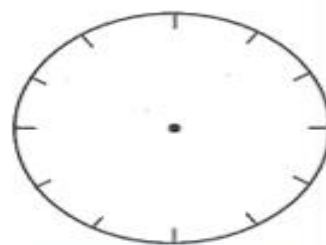
- remove subject from timetable.
- supports to monitor fatigue.



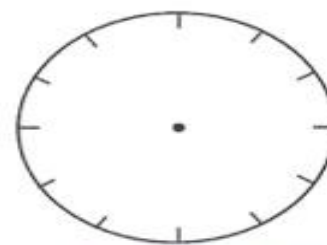
RESOURCES



I LIKE IT



CONFIDENCE



COHERENCE



ONGOING SUPPORT

**Update
School**

Recommend further adjustments

**Letters &
Documents**

**Diagnosis letter, Support letters - reduced load
& VCE – Special Provision forms**

**Join School
meetings**

School Meetings & Professionals Meetings

**Professional
Learning**

Small groups → Whole School

**School
Options**

New school → Alternate Settings → TAFE

**Pathway
Planning**

**Career planning → TAFE →
University Courses &
Documentation**

SHORT COURSE

Impact on school functioning:

WARM UP – short game to break the ice

WWW & EVEN BETTER IF – discussion on what & how we can make school better

SHARING OF IDEAS – strategies & supports

WRITING TASKS – 5 senses poem about CFS that work

DISCUSSION – tips and tricks to studying



Chronic Fatigue

Feels like pain, loneliness, tired, hungry

Sounds like groaning a lot of body cracks, complaining

Tastes like boredom

Smells like boredom

Looks like pale and tired

STUDENT



Chronic Fatigue

Feels like ripping all self-motivation away

Sounds like a trombone low note, a groaning sound

Tastes like salt less food

Smells musky of darkness

Looks deceiving

PARENT



***EVERY YOUNG PERSON
IS UNIQUE AND
SO ARE
THEIR NEEDS***

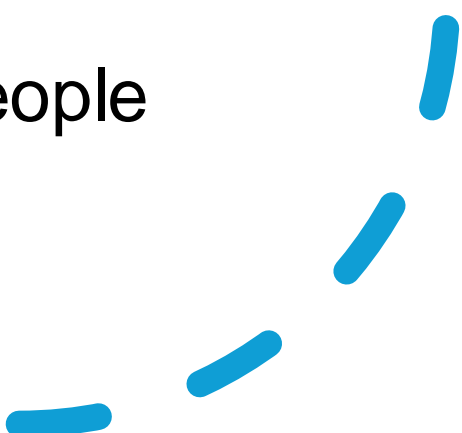


Bringing it all
together –
summary and
questions





Bringing it all together

- Individualised goal setting
 - Importance of empowering young people to self-manage and advocate for self.
 - There are SAFE ways to achieve exercise and participation goals
 - Benefits of peer support from group for young people and their parents.
 - Connection to education and career pathway
 - Benefits of clinicians/young people working with researchers
- 

Thank you and
acknowledgements
to our Monash
Children's VPRS
CFS team and young
people



Questions?



References

- Findlay SM. The tired teen: A review of the assessment and management of the adolescent with sleepiness and fatigue. Paediatr Child Health. 2008 Jan;13(1):37-42. doi: 10.1093/pch/13.1.37. PMID: 19119351; PMCID: PMC2528817
- Stewart JM, Boris JR, Chelimsky G, Fischer PR, Fortunato JE, Grubb BP, Heyer GL, Jarjour IT, Medow MS, Numan MT, Pianosi PT, Singer W, Tarbell S, Chelimsky TC; Pediatric Writing Group of the American Autonomic Society. Pediatric Disorders of Orthostatic Intolerance. Pediatrics. 2018 Jan;141(1):e20171673. doi: 10.1542/peds.2017-1673. Epub 2017 Dec 8. PMID: 29222399; PMCID: PMC5744271.
- Rowe et al , Myalgic Encephalomyelitis/Chronic Fatigue Syndrome Diagnosis and Management in Young People: A Primer Front. Pediatr., 19 June 2017
Sec. Pediatric Neurology Volume 5 - 2017 | <https://doi.org/10.3389/fped.2017.00121>
- Kizilbash SJ, Ahrens SP, Bruce BK, Chelimsky G, Driscoll SW, Harbeck-Weber C, Lloyd RM, Mack KJ, Nelson DE, Ninis N, Pianosi PT, Stewart JM, Weiss KE, Fischer PR. Adolescent fatigue, POTS, and recovery: a guide for clinicians. Curr Probl Pediatr Adolesc Health Care. 2014 May-Jun;44(5):108-33. doi: 10.1016/j.cppeds.2013.12.014. PMID: 24819031; PMCID: PMC5819886

References

- Behnood, S. A. *et al.* Persistent symptoms following SARS-CoV-2 infection amongst children and young people: A meta-analysis of controlled and uncontrolled studies. *J. Infect.* **84**, 158–170
- Jason, Leonard A., et al. "A pediatric case definition for myalgic encephalomyelitis and chronic fatigue syndrome." *Journal of Chronic Fatigue Syndrome* 13.2-3 (2006): 1-44.
- -Tollit M, Politis J, Knight S. Measuring school functioning in students with chronic fatigue syndrome: a systematic review. *J School Health* (2018) 88:74–89. doi: 10.1111/josh.12580
- Rangel L, Garralda ME, Levin M, Roberts H. The course of severe chronic fatigue syndrome in childhood. *J R Soc Med.* (2000) 93:129–34. doi: 10.1177/014107680009300306

References

- Hiremath S et al , Key Features of a Multi-Disciplinary Hospital-Based Rehabilitation Program for Children and Adolescents with Moderate to Severe Myalgic Encephalomyelitis/Chronic Fatigue Syndrome ME/CFS. Int J Environ Res Public Health. 2022 Oct 20;19(20):13608. doi: 10.3390/ijerph192013608. PMID: 36294186; PMCID: PMC9603696.
- Knight S et al. Epidemiology of paediatric chronic fatigue syndrome in Australia. Arch Dis Child. 2019 Aug;104(8):733-738. doi: 10.1136/archdischild-2018-316450. Epub 2019 Feb 23. PMID: 30798255.