Multiple Chemical Sensitivity

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Please note:

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Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters, they are to call the TAPS line for advice.

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Research question: Is multiple chemical sensitivity disorder/idiopathic environmental intolerance a recognised clinical diagnosis in Australia or overseas?

If it is, what are the diagnostic features of the disorder?

What evidence/literature is available to support the aetiology of MCSD?

What medical specialist is best placed to diagnose and/or treat multiple chemical sensitivity disorder (MCSD)?

Are there any clinical guidelines for treatment of MCSD?

Is there any evidence that MCSD can be treated/cured/ameliorated?

Date: 21/12/23

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1. Contents

2. Summary

There is considerable uncertainty regarding the diagnosis, causes and management or treatment of Multiple Chemical Sensitivity (MCS). Symptoms and severity vary widely between individuals. People with MCS symptoms often experience significant functional impact including difficulties with activities of daily living and withdrawal from social and economic participation.

Attempts have been made to achieve consensus on diagnostic criteria for MCS. However, these criteria have been applied inconsistently in scientific and clinical practice. In general, MCS is taken to involve development of non-specific symptoms associated with multiple organ systems after exposure to substances at a lower level than would typically elicit a reaction. Symptoms generally resolve when the irritant is removed.

Due to uncertainty surrounding MCS and the involvement of multiple body systems, it is not clear which medical specialty is best placed to diagnose or treat the condition.

MCS is not recognised as a distinct condition in Australia, though some state health authorities have issued policies or guidelines regarding its treatment. There are no widely agreed

treatment methods. Patient management should involve recognising that person with MCS is experiencing symptoms even if a cause cannot be identified. Symptom management typically involves identifying and avoiding or removing the substance associated with symptom onset.

3. What is Multiple Chemical Sensitivity?

Multiple Chemical Sensitivity is a condition in which varied physical and psychological symptoms are associated with exposure to substances such as drugs, solvents, odorants or materials at a dose that would typically not elicit a harmful reaction in the general population. Each person with MCS may experience different symptoms with varied severity and functional impact. Symptoms are nonspecific and involve multiple body systems and typically resolve when the substance is removed (Hempel et al, 2023; Zucco & Doty, 2022; Damiani et al, 2021).

Despite tens of thousands of publications relating to MCS, there are still only pockets of consensus (Damiani et al, 2021; Multiple Chemical Sensitivity, 1999) and no widespread agreement on its defining characteristics or whether MCS should be considered a distinct condition (Hempel et al, 2023; SA Health, 2023). For example, Bjerregaard et al (2022) limit the scope of MCS to reactions to airborne chemicals. Zucco and Doty (2022) suggest reactants are often petroleum-based, while Damiani et al (2021) include biological agents such as moulds and other microbes.

3.1 Alternative terminology and related conditions

Other terms used to describe MCS include acquired intolerance to solvents, chemical acquired immune deficiency syndrome, chemical injury, chemical hypersensitivity, chemical intolerance, chemophobia, chemical sensitivity; ecological mental illness, environmental hypersensitivity, environmental illness, environmental intolerance, environmental sensitivity, sick building syndrome, symptoms associated with environmental factors, total allergy syndrome, toxicant-induced loss of tolerance, toxic encephalopathy, toxic injury, and twentieth century disease (Hempel et al, 2023; Zucco & Dotti, 2022; Haanes et al, 2020; Department of Health and Ageing, 2010).

Hempel et al (2023) suggest that the lack of terminological consensus reflects a lack of consensus on the clinical features or causes of MCS. Following the World Health Organisation, South Australia's Department of Health (SA Health) suggests that a more contemporary term for MCS is idiopathic environmental intolerance (IEI) (SA Health, 2023; De Luca et al, 2011). IEI may be used as a synonym for MCS, though it has a broader referent. IEI includes reactions to biological and physical agents in the environment such as electromagnetic frequencies, moulds, fungi or other microbes (SA Health, 2023; Safer Care Victoria, 2023).

MCS may also be classified as a sensitivity related illness (De Luca et la, 2011; Genuis, 2010) or functional somatic disorder (Bjeeredaard et al, 2022). MCS is often compared with food

intolerances, allergy conditions and sensitivity-related conditions with non-specific symptoms for which recognisable causes have not been found such as fibromyalgia, Gulf War syndrome, chronic fatigue syndrome, sick building syndrome, and electromagnetic radiation exposure (Zucco & Doty, 2022; De Luca et la, 2011). People with MCS are frequently diagnosed with one or more of these other conditions (Bjeeredaard et al, 2022), though some suggest their presence should exclude a diagnosis of MSC (Driesen et al, 2020).

3.2 Classification and recognition as a distinct condition

There is ongoing debate among researchers whether MCS is primarily psychogenic or pathogenetic, and therefore whether it should be considered a psychiatric condition or another type of medical condition (Molot et al, 2023; Molot, 2021; Carrier et al, 2021). Further, there is no clear consensus on whether MCS is a distinct condition (Hempel et al, 2023; SA Health, 2023; Zucco & Doty, 2022; Rossi & Pitidis, 2018).

In 2011, De Luca et al identified difficulties preventing a clinical consensus on the classification and recognition of MCS:

> (i) the wide array of symptoms and signs allegedly linkable to environmental triggers exposure, (ii) the diversity of the subjects affected, reacting on the basis of individual sensitivity and possibly genetic predisposition, (iii) the mere absence of proven pathogenic mechanisms and consequently of clear-cut diagnostic criteria, (iv) the wide spectrum of possible triggers and the absence of clear dose-dependent reactions, generating methodological difficulties and bias in provocation studies (De Luca et al, 2011, p.2771).

Despite the recent research and public health interest in MCS, the situation has not changed from De Luca et al's description (Hempel et al, 2023; SA Health, 2023; Zucco & Doty, 2022; Rossi & Pitidis, 2018).

4. Population characteristics

People diagnosed with MCS or who self-identify as having MCS are more likely to be women of middle age, with higher educational achievement and higher socioeconomic status (Zucco & Doty, 2022; Bjerregaard et al, 2022). People diagnosed with MCS may be more likely to have asthma, chronic fatigue syndrome, fibromyalgia and sedentary or inactive lifestyles (Bjerregaard et al, 2022; Steineman, 2018a-b).

5. Symptoms

People with MCS have reported symptoms including: dizziness, fainting confusion, brain fog, memory loss, fever, seizures, mood changes, irritability, anxiety, depression, headache, chest pain, changes in heart rhythm, nausea, abdominal pain, bloating, gas and diarrhoea, fatigue, nasal congestion, itching and sneezing, shortness of breath, asthma attacks, flu-like symptoms, skin rashes, muscle weakness, muscle and joint pain (Hempel et al, 2023; Safer Care Victoria, 2023; SA Health, 2023; Dreisen et al, 2020; Steineman, 2018a).

In a survey study of 1098 Australians (Steineman, 2018a), the most common symptoms reported in the sample were respiratory (47%, eg. difficulty breathing, coughing, shortness of breath) and mucosal symptoms (41%, eg. watery or red eyes, nasal congestion, sneezing). Other frequent symptoms included migraines (31%) and skin problems (32%).

6. Triggers

Common substances that trigger symptoms in people with MCS include carpeting, soft furnishings, printing ink, plastics, synthetic fabrics, soaps, shampoos and other cleaning products, perfumes, air fresheners and deoderants, foods, anaesthetics and other pharmaceuticals, paints, glues, solvents, formaldehyde, pesticides, herbicides, cigarette smoke, wood smoke, mould, chlorinated and fluoridated water, carbon monoxide, mercury (Hempel et al, 2023; Safer Care Victoria, 2023; SA Health, 2023; Zucco & Doty, 2022; Driesen et al, 2020). A common feature of these substances may be smell (Carrier et al, 2021; Steineman, 2018a-b), though this is disputed (Molot et al, 2023).

7. Functional impact

In their survey study, Steineman found potentially disabling health effects were reported in 55.4% of respondents with MCS (Steineman, 2018a). Furthermore, 77.5% of people with MCS reported avoiding places because of fragranced products and 52.1% had missed work or lost a job because of exposure to fragranced products in the workplace (Steineman, 2018a). Another survey study from the same author found that 76% of American respondents with MCS reported potentially disabling health problems (Steineman, 2018b).

Steineman's results must be taken with caution due to the demographic inconsistency with other studies. In particular, the proportion of women and men diagnosed with MCS does not agree with the majority of other studies, which find significantly more women than men diagnosed with MCS (Zucco & doty, 2022; Bjerregaard et al, 2022). One study (Steineman, 2018a) found only a slightly increased percentage of women diagnosed with MCS (49.5%/50.5%), and the other (Steineman et al, 2018b) found a much higher percentage of men diagnosed with MCS (58%/42%).

Driesen et al (2020) reviewed 13 qualitative studies analysing social and occupational impact of MCS. They found participants consistently reported limited access to relationships, social

settings, work and other occupational settings due to lack of understanding or accommodations and the continued presence of fragrances and other triggers in social and occupational environments. Participants also reported reduction in quality of life due to reduced income or reduced social engagement. The frequent reporting of withdrawal from social and economic activities agrees with Steineman's (2018a; 2018b) survey findings. However, Driesen et al (2020) suggest caution in interpreting the results due to significant quality concerns with the reviewed studies including lack of rigour in design and analysis and failure to report ethics standards or approval. They also found just under half of the studies were conducted by a single research team, potentially biasing results.

Bjerregaard et al (2022) suggest that activity limitation may be due to health effects such as respiratory issues and pain as well as the avoidance of triggers. This may be partly due to coincidence of MCS and other conditions such as fibromyalgia, chronic fatigue syndrome or irritable bowel syndrome.

8. Cause

There is no consensus on the cause of MCS (SA Health, 2023; Safer Care Victoria, 2023). Some argue that the illness is primarily psychogenic and therefore should be classed as a psychiatric disorder (Carrier et al, 2021). Others argue that there are pathophysiological mechanisms underlying the illness (Molot et al, 2023; Molot, 2021).

9. Diagnosis

An Italian group (Damiani et al, 2021) proposed screening and diagnosis should include first round blood tests, followed by administering the Brief Environmental Exposure and Sensitivity Inventory and the Quick Environmental Exposure and Sensitivity Inventory (Söderholm et al, 2021). At which point diagnosis can be made according to the following criteria:

- presence for over 6 months with a worsening of both quality of life and organic functions
- recurrent and reproducible symptoms also involving the nervous system with a characteristic hypersensitivity to odours
- symptoms involving the central nervous system and at least one other symptom
- reproducible responses to triggers at a low concentration
- a response to unrelated chemicals
- an improvement of symptoms or even a complete resolution after the removal of the trigger (Damiani et al, 2021).

However, this process has not been consistently implemented and there is currently no widely agreed upon diagnostic practice or set of diagnostic criteria (Binkley, 2023; Hempel et al, 2023; SA Health, 2023; Zucco & Doty, 2022).

10. Management

Many treatment and management strategies have been proposed to address MCS. However, because there is no agree aetiology, it is unclear what systems or functions a treatment should target (Molot et al, 2023; Zucco & Doty, 2022).

There is some evidence that standard treatments for mental health concerns, such as cognitive behavioural therapy, can alleviate these symptoms in people with MCS (Binkley, 2023). However, at present the only consistent recommendation is trigger avoidance (SA Health, 2023; Safer Care Victoria, 2023; Molot et al, 2023; Zucco & Doty, 2022).

It is not clear what medical specialty is best placed to manage people with MCS. If MCS is primarily a psychiatric condition, a psychiatrist or mental health specialist is likely to be the most appropriate clinician (Carrier et al, 2021). However, it has also been suggested that a GP is the most appropriate primary care provider due to their experience with unspecified illnesses and overall health (Department of Health and Ageing, 2010).

11. Multiple Chemical Sensitivity in Australia

Some Australian governments, government departments, or agencies and organisations associated with Australian governments, have published policies, statements or guidelines regarding MCS/IEI. There is a common approach among these resources that the symptoms of MCS/IEI can cause significant distress and reasonable adjustments can be made by institutions and service providers.

Federal

MCS/IEI does not occur in the Australian modification to the International Classification of Disease (Independent Health and Aged Care Pricing Authority, 2022) and is not a recognised medical condition in Australia (SA Health, 2023; Australian Disability Clearinghouse on Education and Training, n.d. a).

A 2010 report from the federal Department of Health and Ageing notes:

> The proposal to assign a unique classification code for MCS in 2003 was rejected. The experts concluded that there was a lack of clinical or laboratory evidence of a pathological process, difficulties in delineating patients from others within a wide spectrum of intolerance/irritation from smells and fumes in the general population, a lack of internationally accepted diagnostic criteria or validated diagnostic tests and a lack of clarity of the relationship between MCS and other syndromes with overlapping clinical features e.g. chronic fatigue syndrome or fibromyalgia (Department of Health and Ageing, 2010, p.15)

At the same time, the report acknowledges that symptoms of MCS can have a substantial effect on people's lives:

> Clinicians need to accept the patient's issues as a debilitating and disabling illness irrespective of whether the clinician recognises or accepts the presence of a condition, in order to minimise patients seeking unnecessary referrals and harmful or costly but non beneficial treatment. …The basic management, as with all chronic illness, involves engaging with the patient and maintaining a long-term supportive relationship whilst encouraging self-management (Department of Health and Ageing, 2010, p.71-72).

The Australian Disability Clearinghouse on Education and Training (ADCET) are funded by the Australian federal Department of Education and hosted by the University of Tasmania. ADCET (n.d.) published a report from consultancy firm DLM Solutions (Leahy & Evans, 2015) which argues for increased recognition and accommodation for people with MCS/IEI. The ADCET's role is to disseminate information relating to disability and education. They note that they take quality control measures before publishing information but also that publication on the ADCET's website does not mean that the content is endorsed by ADCET or the Department of Education (ADCET, n.d. b).

The Australian Radiation Protection and Nuclear Safety Agency (ARPANSA) has published advice on a related condition: idiopathic environmental intolerance attributed to electromagnetic fields (IEI-EMF), also called electromagnetic hypersensitivity:

> On the basis of current scientific information, there is no established evidence that EHS is caused by EMF at levels below exposure guidelines. ARPANSA acknowledges that the health symptoms experienced by the affected individuals are real and can be a disabling problem, and advise those affected to seek medical advice from a qualified medical specialist (ARPANSA, n.d.).

Other sources have referred to a guideline from the Australian Human Rights Commission regarding access for people with chemical sensitivity (NSW Health, 2015; ADCET, n.d. a). However, this document is no longer stored on the Human Rights Commission website.

New South Wales

NSW Health (2015) describes the Department of Health and Ageing report (2010) and an Australian Human Rights Commission guideline (no longer available) and advises "Reasonable accommodations should be made to support people who identify as having MCS and who have a treatment plan by a registered medical practitioner when they attend NSW Health facilities."

Victoria

Safer Care Victoria is an administrative unit of the Victorian state government that advises health services on how to provide safer, evidence-based services. Their MCS clinical guideline (Safer Care, 2023) provides some general information about MCS while acknowledging that symptoms of MCS can cause suffering and disability.

South Australia

The SA Health (2023) fact sheet on IEI acknowledges that MCS/IEI "is not recognised as a medical condition in Australia and most countries". The factsheet advises that the service providers should aim to develop a respectful relationship with people experiencing symptoms of MCS/IEI. This may include identifying triggers and modifying the environment as far as possible.

Older guidelines

The West Australian Country Health service (2012) published an MCS guideline for hospital and other service providers. This was based on the South Australian approach. It is not clear if the guideline is still endorsed by the West Australian government.

Queensland health has previously stated that the government does not "categorise MCS as a recognised clinical syndrome due to the absence of clinical consensus", however "patients who classify themselves as suffering from MCS may have health needs that require treatment in the public health system, and therefore should receive individualised medical and psychological assessment and treatment as determined by the treating medical officer" (Queensland Health, 2011, p.7). The position statement is no longer available on the Queensland Health website and it is not clear if they have an updated policy.

Canberra Health Services included a policy on MCS in 2016 (Canberra Hospital and Health Services,2016). The document still appears to be hosted by the ACT government but is not listed in their hospital policies.

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Research Request – Multiple Chemical Sensitivity and the impact of chlorine on Testosterone production

Brief	Is there any research or evidence for the following: • Has Chemical Sensitivity been linked to the diagnoses listed? • Have there been any side effects identified from salt water pool exposure • Has Thermoregulation issues been linked to the diagnoses listed? • Has prolonged exposure to chlorine been linked to diminished testosterone levels? • Do diminished testosterone levels result in chemical sensitivity and/or thermoregulation issues? Diagnoses: ABI, Epilepsy, moderate to severe static encephalopathy, hemiparesis, pan hypopituitarism, cognitive impairment, marked dysarthric speech and intractable nocturnal multi-focal seizures.
Date	31/08/2020
Requester	Naomi s47F - personal pr (Senior Technical Advisor TAB/AAT)
Researcher	Jane s47F - personal priv (Research Team Leader)

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1. What is Multiple Chemical Sensitivity (MCS)?

Multiple Chemical Sensitivity (MCS) is the most common term used to describe a condition presenting as a complex array of symptoms linked to low level chemical exposures. The underlying mode(s) of action of MCS, i.e. the biological mechanisms by which the chemical sensitivity occurs, remain uncertain [1].

A common theme reported by individuals is experiences of heightened responsiveness to chemicals at extremely low exposure levels. Sufferers identify a remarkably wide and diverse range of chemical, biological and physical factors as symptom triggers. Most commonly, the literature mentions the following as potential triggers of symptoms [2]:

- Carpeting, printing ink, soft plastics, synthetic fabrics
- Chlorinated and fluoridated water
- Cigarette smoke
- Cleaning products
- Electromagnetic field
- Fragranced products such as perfumes, aftershave, and deodorants
- Pesticides
- Pharmaceutical drugs and anaesthetics
- Volatile organic compounds, including paint and solvents

Similarly, the symptoms experienced by individuals from exposures are diverse and involve multiple organ systems. Although non-specific neurological symptoms are common, overall there is no characteristic symptom profile that identifies MCS. Nevertheless, reported symptoms can, in some cases, be debilitating [2].

A study by Ross et al. [3] found that symptoms fell into three groups:

1. Central nervous system
2. Respiratory system
3. Gastrointestinal system

The table below shows the percentage prevalence of symptoms reported by Ross et al [3]:

Symptom	Prevalence (%) #
Headache	55
Fatigue	51
Confusion	31
Depression	30

Symptom	Prevalence (%) #
Shortness of Breath	29
Arthralgia	26
Myalgia	25
Nausea	20
Dizziness	18
Memory problems	14
Gastrointestinal symptoms	14
Respiratory symptoms	14
# The percentage of MCS patients exhibiting a particular symptom	

Numerous modes of action have been postulated for MCS. These include immunological changes, respiratory/neurogenic inflammation, limbic sensitisation, elevated NMDA receptor activity, altered metabolism as well as behavioural conditioning and psychological disorders [1].

At this time, worldwide, MCS is not an internationally classified disorder as the illness is not associated with objective medical findings, and mainstream medicine largely has rejected the notion that MCS constitutes a pathophysiological entity [1].

Presently, a diagnosis of MCS is based commonly on self-reported symptoms and chemical exposure histories [1]. The symptom profile of MCS is indistinguishable from other multi-symptom disorders. No laboratory tests currently exist for diagnosing MCS [1]. Different case definitions and the lack of a characteristic symptom profile and objective laboratory biomarkers for MCS have impeded recognition of the disorder as a distinct clinical entity [1].

There are no standardised treatments for MCS. Current treatments advocated for MCS include [1]:

- Dietary changes
- Nutritional supplements
- Detoxification and desensitisation techniques
- Holistic or body therapies
- Prescription medicines
- Behavioural therapies

The most common management regime for MCS is avoidance of agents that trigger symptoms [1].

2. Has Chemical Sensitivity been linked to the diagnoses listed?

The pathogenesis of MCS is unknown pathogenesis. No research could be sourced supporting a direct link between the onset of MCS and:

- Head trauma/acquired brain injury
- Moderate to severe static encephalopathy
- Hemiparesis
- Pan hypopituitarism
- Cognitive impairment **(memory problems and confusion are symptoms of MCS)**
    - MCS often is associated with subjective cognitive complaints, but neuropsychological reviewers of MCS have concluded that there is no evidence of cognitive deficits [4, 5].
- Marked dysarthric speech
- Intractable nocturnal multi-focal seizures

A single case study has reported co-existing MCS and **epilepsy** [6]. However, the patient (a 23-year old female) reported that symptoms of MCS preceded the onset of epilepsy. MCS symptoms began at age 1 (gastrointestinal symptoms and/or change in body temperature induced by the smell or ingestion of causative chemicals) and started to suffer partial seizures at age 17. The delivery of the anti-epileptic drug Levetiracetam improved recurrent symptoms of MCS. The authors note that further randomised trials are required to confirm the efficacy of this treatment.

There is an overlap in symptomology and clinical findings between MCS, fibromyalgia and chronic fatigue syndrome which are also conditions which are medically unexplained [7]. One study found that a diagnosis of fibromyalgia and chronic fatigue syndrome are common among MCS patients (75% and 85% respectively) [7].

3. Have there been any side effects identified from salt water pool exposure?

A saltwater pool is an alternative to a traditional chlorine pool. Although you don't add chlorine tablets to a saltwater pool, it does still contain chlorine. It just has a smaller amount that's generated through the filter system.

Since chlorine is still present in the pool (just at a lower level), there are still the negative side effects associated with chlorinated pools [8]. These include but aren't limited to the chlorine smell, irritation to the swimmers eyes and lungs, and bleaching of swimsuits and pool covers. Prolonged exposure to chlorine, especially to children, can lead to "swimmers lung" and

asthma. Since the levels of chlorine are lower than that of a traditionally chlorinated pool, these side effects are minimized.

Some blog posts have suggested that saltwater can reduce skin inflammation and calm the immune system, however, this is just opinion rather than scientific fact.

4. Has Thermoregulation issues been linked to the diagnoses listed?

Several aetiologies related to endocrine imbalances may cause decreased heat production. These include hypopituitarism/panhypopituitarism, hypoadrenalism, and hypothyroidism. Other causes include severe malnutrition or hypoglycemia and neuromuscular inefficiencies seen in the extremes of age [8, 9].

A variety of causes may also be associated with impaired thermoregulation, but, generally, it is associated with failure of the hypothalamus to regulate core body temperature. This may include Panhypopituitarism which is due to inadequate or absent production of the anterior pituitary hormones. It is frequently the result of other problems that affect the pituitary gland and either reduce or destroy its function or interfere with hypothalamic secretion of the varying pituitary-releasing hormones [8, 9].

5. Has prolonged exposure to chlorine been linked to diminished testosterone levels?

Rodent studies have demonstrated that at high doses several chlorination by-products among the haloacetic acids (HAAs) and haloacetonitriles (HANs) and trihalomethanes (THMs) can damage the testes and disrupt spermatogenesis [10-13]. Although there is a widespread human exposure to these potential toxins, to date, only two epidemiological studies have assessed their possible impact on testicular function.

Investigating a small cohort of healthy volunteers, Fenster et al. (2003) [14] found that exposure to THMs in tap water was associated with decreased sperm mobility but these findings were not confirmed by Luben et al. (2007) [15]. However, these two studies, addressed the risks via the consumption of drinking water.

Only a single cross-sectional study could be located that investigated the associations between testicular hormones at adolescence and the exposure to chlorination by-products when attending chlorinated swimming pools [16].

- 361 school male adolescents (aged 14–18 years) in Belgium who had visited swimming pools disinfected with chlorine or by copper–silver ionization.

- Parental questionnaire to determine time spent in chlorinated pools (indoor and outdoor), height and body weight and the collection of a blood sample.
- Adolescents having attended indoor chlorinated pools for more than 250 h before the age of 10 years or for more than 125 h before the age of 7 years were:
    - 3x more likely to have an abnormally low serum inhibin B and/or total testosterone than their peers who never visited this type of pool during their childhood (odds ratio, 95% CI, 2.83, 1.06–7.52, p = 0.04 and 3.67, 1.45–9.34, p = 0.006, respectively)
    - Same association wasn't see for free testosterone

Limitations

1) Potential for individual characteristics to influence results such as height, weight, breast fed as a child, parental smoking, difference in percentage/time spent at indoor and/or outdoor chlorinated pools which were all significantly different between the 3 included groups of adolescents
2) Testosterone level continues to change up until the age of 17 (mean age 15.5) which means lifetime testosterone levels may not be impacted
3) Tanner stage (sexual maturity rating) or the testes size were not measured
4) Sample size was moderate in size. Larger sample may elicit different results

6. Do diminished testosterone levels result in chemical sensitivity and/or thermoregulation issues?

No research could be sourced which supports a link between diminished testosterone levels, the onset of MCS and/or thermoregulation issues.

7. References

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13. Linder RE, Klinefelter GR, Strader LF, Narotsky MG, Suarez JD, Roberts NL & Perreault SD. (1995) Dibromoacetic acid affects reproductive competence and sperm quality in male-rat. Fundam Appl Toxicol 28, 9–17.

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Research - DRHS:

- **Health Conditions with a Thermoregulation or Temperature Sensitivity Factor**
- **Link to Air Conditioning/Heating supports**

Brief	1. **Thermoregulation and heat loss**
	2. **TAT advices** - Analysis of previous TAT advices relating to AC.
	3. **Link to disability -** Analysis of types of health conditions that have a thermoregulatory or temperature sensitivity factor.
	  ○ Any link to AC/heating being an effective preventative or treatment measure.
	  ○ Evidence as to when the need for AC/heating as a support would be considered to be related to the disability (and which ones).
	4. **Value for money -** Costs of the AC if considered for funding, and power usage, given we may be up for ancillary costs. I.e. Split systems versus portables. Also look at AC system life expectancy.
	5. **Other Options** - Evidence as to whether AC would be considered first option to address need i.e. other AT supports which may address need such as cooling vests etc.
	6. **AC usage** - Evidence as to usage of AC in different cities i.e. how may be considered usual daily living expense (have attached previous email info about this.

Date	25/10/19
Requester	TAT Research Team
Researcher	Aanika s47F - perso & Craig s47F - pers

Contents

Note: Separate research into the Commonwealth/state/territory power subsidy schemes for medical equipment and heating/cooling has also been collated, which links into air conditioning running costs.

Note: where full journal articles were not accessible, abstract information has been used.

Related TAB Research

NED20/191674 : RES HWB/AT Thermoregulation Dysfunction and Seizures

Commented [HA1]: Incorporate in RES 042

Thermoregulation in Humans

Commented [HA2]: This section should be reworked as "Understanding thermoregulation in humans" and may include parts of the next section as well ("Types of heat loss")

Humans are usually in a thermal steady state with respect to their surroundings. As endotherms, humans control their body temperatures. Heat generated by metabolic processes is lost to the environment though several mechanisms: radiation, conduction, convection, and evaporation. Unless the organism has more heat than can be eliminated by radiation and convection, evaporation (through perspiration) is not required and conduction is negligible[1].

- Normothermia - 36.5–37.5 °C
- Hypothermia - <35.0 °C
- Hyperthermia - >37.5 or 38.3 °C
- Fever - >37.5 or 38.3 °C
- Hyperpyrexia - >40.0 or 41.0 °C

A publication from 2014 in the Handbook of Clinical Neurology states that normally in the human body heat is dissipated by means of a thermoregulatory system.

- "Disorders resulting from abnormally high or low body temperature result in neurologic dysfunction and pose a threat to life. In response to thermal stress, maintenance of normal body temperature is primarily maintained by convection and evaporation. Hyperthermia results from abnormal temperature regulation, leading to extremely elevated body temperature while fever results from a normal thermoregulatory mechanism operating at a higher set point. The former leads to specific clinical syndromes with inability of the thermoregulatory mechanism to maintain a constant body temperature. Heat related illness encompasses heat rash, heat cramps, heat exhaustion and heat stroke, in order of severity. In addition, drugs can induce hyperthermia and produce one of several specific clinical syndromes. Hypothermia is the reduction of body temperature to levels below 35°C from environmental exposure, metabolic disorders, or therapeutic intervention. Management of disorders of body temperature should be carried out decisively and expeditiously, in order to avoid secondary neurologic injury"[2].

Types of heat loss

Commented [HA3]: Physiological elements of this section should be incorporated in the "understanding thermoregulation in humans" section. Other elements can be incorporated into a section called "Heating and cooling systems".

Heat loss (external heat flow) can occur via four pathways: radiation, convection, conduction and evaporation of water[3].

[1] Dr Physics, 'Heat transfer and the human body', https://www.drphysics.com/convection/convection.html, accessed 12 October 2019.
[2] Gomez, CR, 'Disorders of body temperature', Handbook of Clinical Neurology, Vol.120, 2014, pp. 947-957, https://www.sciencedirect.com/science/article/pii/B9780702040870000620?via%3Dihub, accessed 14 October 2019.
[3] Szakacs, J, 'Disorders of Thermoregulation', [presentation], http://web.med.u-szeged.hu/patph/Thermoregulation, accessed 10 October 2019.

Radiation

- Infrared radiation is the heat transfer between the body and nearby human beings or objects with lower temperature. As long as air temperature is less than body temperature, 65% of the body's heat is lost by radiation.
- **Human bodies will radiate heat into the environment in order to lose it.**

Conduction

- Conduction is the transfer of heat to the surrounding, cooler environment via direct physical contact. It accounts for 2% of the body's heat lost.
- **Cooling vests are an example of conduction as the heat moves into the cooler object.**

Convection

- When the surrounding air is warmed up by the skin, it is replaced by a cooler layer. Convection and conduction are enhanced by a breeze or by a cooler fluid medium. It is influenced by the blood circulation of the skin. It accounts for 10% of the body's heat loss.
- **Air conditioning is an example of convection.**

Evaporation of water

- During heavy exertion or at high surrounding temperature (>36 oC) heat dissipation occurs entirely by evaporation Influenced by: blood circulation, humidity and temperature of the air, wind. When the humidity of the air (e.g. tropical rainforest) increases, heat loss through sweating decreases considerably or cease completely
    - Perspiratio insensibilis: through the skin and the airways ~ 1 l/day
    - Perspiratio sensibilis: via the activated sweat glands ~ 10 l /day
- **For example, evaporation of sweat (water to gas).**

Passive and Active Cooling

Passive Cooling is probably the most widely used type of cooling. It is called passive, as it does not rely on a power source to cool, but rather cools through the use of ice packs or gel. Passive cooling is generally inexpensive and portable, but has the disadvantage of limited duration of cooling, as the devices themselves require re-cooling every two to four hours. They also can be heavy.

Commented [AH4]: This is not what passive cooling is.

Active Cooling is a somewhat more "high tech" approach to cooling. Rather than achieving cooling through ice packs or gel packs, active cooling uses a motorized system to circulate cold water around the body"[4].

[4] DiCarrado, S & Karpatkin, H, ' Active and passive cooling garment options for persons with MS', Multiple Sclerosis Foundation, 2016, https://msfocus.org/Magazine/Magazine-Items/Posted/Be-Cool-with-Active-and-Passive-Cooling-Garments-O.aspx, accessed 10 October 1029.

Analysis of Air Conditioning related TAT Advices

Commented [AH5]: REMOVE sections on TAT Advices

TAT Advices from 22/05/17 to 12/09/19 loaded onto HPRM were analysed for key issues and themes which might be supportive for a delegate to make an informed R&N decision, taking into account the link with the participant's disability and thermoregulation.

Recommendations not to fund

Of the 17 advices 15 were recommended to not fund. It appears these were based on:

- Insufficient evidence that air-conditioning of the participant's home is value for money relative to the benefits achieved and the cost of alternative supports.
- There is no evidence that it will improve the life-stage outcomes for the participant (rule 3.1b) or reduce the need for other types of NDIS funded supports now or in the future (rule 3.1f).
- Air-conditioning or heating is the responsibility of any home owner/ tenant to provide for comfort during hot temperatures.
- The supply and installation of an air-conditioning unit is considered a day-to-day living cost and the responsibility of the home owner to fund.

Recommendations to fund

Of the 17 advices only two recommended funding. Both advices related to a thermoregulation issue with the participant being at risk of Autonomic Dysreflexia. Both participants have Spinal Cord Injury.

The recommendations were based on the link between the participant's disability (Spinal Cord Injury) and thermoregulatory dysfunction.

- Advice: 2018 8130 / NED19/185598 was not declined as there was a link between the participant's disability and thermoregulatory dysfunction:
  Further enquiry from Advisor on 26/09/19 - *"My advice in 2018 8130 was informed by the clear link between the participant's disability (high level SCI, above T6) and thermoregulatory dysfunction/AD. The research referenced in the advice links both poor functional outcomes as well as risk of life threatening health complications to thermoregulatory dysfunction and AD. There was also evidence of all other R&N criteria being met. In particular, there was evidence that this participant would not otherwise have funded a/c in his living area and that there was not a day-to-day cost of living component, as there can frequently be with a/c advices"*.
- Advice: 2019 1164 / NED19/185733 was not declined as there was a link between the participant's disability and thermoregulatory dysfunction:
  Further enquiry from Advisor on 26/09/19 - "... this participant also experiences autonomic dysreflexia and thermoregulatory dysfunction as a result of high level SCI. We have evidence from her treating medical practitioner of this, referenced in the advice. Please note that this is a second advice in relation to air con for this participant, there were additional documents referenced in the original advice, referred to in this one"

A full breakdown of the TAT advices that were analysed can be found in Appendix A.

Funding of Air conditioning in public housing

In 2018 the TAT received a request to approve funding for an air-conditioner for a child with cerebral palsy and uncontrolled seizures living in QLD public housing (20185188). The key question was whether air conditioning was more appropriately funded by the QLD Department of Housing or the NDIS.

A position was put forward to clarify that the NDIS is not responsible for the funding of air conditioning in publicly provided housing as this:

- Does not meet section 34(1)(f) f the NDIS Act.
- Overlooks the obligations of the housing authority under the *Disability Discrimination Act 1992* to make reasonable adjustments to housing for people with disability related needs.
    - The two largest QLD state government authorities have established policy which accepts their responsibility to provide air conditioning in public housing where medical or disability related need is demonstrated

This position separates considerations for the possible NDIS funding of air conditioning in private homes, from funding considerations in public housing.

Disability Types and Health Conditions with Thermoregulation Control Factor

Overview

There are numerous health conditions that have a thermoregulatory (inability to regulate body temperature) or heat or cold sensitivity factor. The list of health conditions below have been identified and collated from two sources:

- TAT advices; and
- Australian heating and cooling energy subsidy schemes.

There may be other health conditions that require heating or cooling supports.

The health conditions listed in the heating and cooling energy subsidy schemes clearly have a thermoregulation link. Of the TAT advice health conditions, Spina Bifida was the only one where there was no readily available evidence to support the link between Spina Bifida and an inability to regulate heat.

Note: While every attempt to locate contemporary and correct information was made, this information collated below may not be medically accurate.

Commented [HA6]: Do not include data from advices, but can use them to point to other pieces of evidence.

Commented [HA7]: Emphasise: not an exhaustive list. Would be useful to describe which types of impairment in body function (ICF) can contribute to thermoregulation problems.

Disability types / health conditions with [;l=-thermoregulatory factor identified:

From TAT advices:	State and territory medical heating and cooling energy subsidy schemes identify the following health conditions as potentially having a thermoregulatory component:
• Spinal Cord Injury • Multiple Sclerosis • Junctional Epidermolysis Bullosa • Spina Bifida • Stroke • ASD • ABI • Fanconi Anemia • Cerebral Palsy	• Epilepsy – heat induced seizures • Parkinson's Disease • Fibromyalgia • Muscular Dystrophy • Systemic Lupus Erythematosus (SLE) • Motor Neurone Disease • Lymphoedema (>Grade 1) • Post-Polio syndrome/Poliomyelitis • Tetraplegia (quadriplegia) • Familial disautonomia (a genetic disorder affecting individuals' automatic (involuntary) bodily responses • Scleroderma • Complex Regional Pain Syndrome

Some of these conditions only have an associated need for **heating** or **cooling** supports to maintain body temperature, while others have thermoregulation issues requiring supports for both.

Spinal Cord injury (SCI) / Tetraplegia / Quadriplegia

Cooling

The two TAT advices where funding for air conditioning was recommended were both related to the participant having spinal cord injury above T6, and at risk of autonomic dysreflexia (AD) . Autonomic dysreflexia is a condition of uncontrolled sympathetic response secondary to a precipitant, which generally occurs in patients with injury to the spinal cord at levels of T6 and above[5].

According to Health Queensland: "People with SCI at the level of T6 and above can lack the control to respond appropriately to environmental changes in temperature. As a result, they may experience high or low body temperatures and this can be of particular concern in the summer season. Most people with this level of injury will require air conditioning in their home, car and workplace[6].

NSW Health also states that: "Autonomic dysreflexia in a person with SCI can present in a variety of ways and vary in intensity from mild discomfort to a severe, life threatening medical emergency. Typically, the patient will complain of a pounding headache with flushing and profuse sweating above the level of spinal lesion, with or without other symptoms such as nasal congestion (stuffiness), blurred vision, shortness of breath and/or anxiety"[7].

In 2017 a controlled study was undertaken to compare the effects of heat exposure on cognition in persons with tetraplegia compared to a group of able-bodied controls. "To determine the effects of heat exposure on core body temperature (Tcore) and cognitive performance in persons with tetraplegia, 8 individuals with chronic tetraplegia (C3-C7, American Spinal Cord Injury Association Impairment Scale A-B) and 9 able-bodied controls were acclimated to 27°C at baseline (BL) before being exposed to 35°C for up to 120 min (Heat Challenge)".

The study confirmed that:

- "Dysfunctional thermoregulatory mechanisms in the tetraplegic group allowed Tcore to rise from subnormal levels to normothermia (normal body temperature) during heat exposure. Normothermia was associated with improvements in attention, working memory, and executive function"[8].

Research clearly indicates that people with spinal cord injury above T6 have difficulties with thermoregulation and are particularly at risk of life threatening complications from overheating.

Multiple Sclerosis

Heating and **Cooling**

In 2010, the Journal of Applied Physiology published a review into the impact of thermoregulation as a symptom for people with multiple sclerosis.

The review found that:

[5] J. Bycroft et al., "Autonomic dysreflexia: a medical emergency", Postgraduate Medical Journal, 2005, pp. 232-235. https://pmj.bmj.com/content/81/954/232, accessed 10 October 2019.
[6] Queensland Government, Queensland Health, "Spinal Outreach Team Newsletter", Issue 21, Jan 2018. https://www.health.qld.gov.au/__data/assets/pdf_file/0028/690841/spot-news-2018.pdf
[7] Middleton, J et al., 'Treatment of Autonomic Dysreflexia for Adults & Adolescents with Spinal Cord Injuries', NSW Agency for Clinical Innovation, 2013, https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0007/155149/Autonomic-Dysreflexia-Treatment.pdf, accessed 14 October 2019.
[8] Handrakis, JP et al., 'Effect of Heat Exposure on Cognition in persons with Tetraplegia', Journal of Neurotrauma, vol. 15, no. 34, 2017, pp. 3372-3380, https://www.ncbi.nlm.nih.gov/pubmed/28462685, accessed 15 October 2019.

- "Multiple sclerosis (MS) is a progressive neurological disorder that disrupts axonal myelin in the central nervous system. Demyelination produces alterations in saltatory conduction, slowed conduction velocity, and a predisposition to conduction block.
- An estimated 60–80% of MS patients experience temporary worsening of clinical signs and neurological symptoms with heat exposure. Additionally, MS may produce impaired neural control of autonomic and endocrine functions.
- This review focuses on five main themes regarding the current understanding of thermoregulatory dysfunction in MS: *1) heat sensitivity; 2) central regulation of body temperature;* 3*) thermoregulatory effector responses;* 4*) heat-induced fatigue; and* 5*) countermeasures to improve or maintain function during thermal stress.*
- Heat sensitivity in MS is related to the detrimental effects of increased temperature on action potential propagation in demyelinated axons, resulting in conduction slowing and/or block, which can be quantitatively characterized using precise measurements of ocular movements.
- MS lesions can also occur in areas of the brain responsible for the control and regulation of body temperature and thermoregulatory effector responses, resulting in impaired neural control of sudomotor pathways or neural-induced changes in eccrine sweat glands, as evidenced by observations of reduced sweating responses in MS patients. Fatigue during thermal stress is common in MS and results in decreased motor function and increased symptomatology likely due to impairments in central conduction"[9].

Regarding effective treatment, the review concluded that:

- "Although not comprehensive, some evidence exists concerning treatments (cooling, precooling, and pharmacological) for the MS patient to preserve function and decrease symptom worsening during heat stress"
- "Cooling techniques, including precooling, have been shown to be effective in minimizing the consequences of heat stress in MS patients. Advances in pharmacological therapies have demonstrated potential in limiting symptom worsening during heat exposure and warrant further investigation"[10].

Multiple Sclerosis Australia acknowledge that people with MS commonly experience heat sensitivity and flare ups when hot. MS Australia recommends a variety of personal and environmental cooling strategies to reduce symptoms flare up. A key environmental strategy is to: "Keep your home cool - use a fan, air conditioner or evaporative cooler". MS Australia also state that "sensitivity to cold is not as well-known as heat sensitivity, but both occur quite frequently in MS. Some people are sensitive to both heat and cold so the temperature needs to be just right for them to feel at their best"[11].

Multiple Sclerosis Foundation discuss the different types of cooling options available and differentiate between active and passive cooling. MS Foundation advise that:

- "Almost all persons with multiple sclerosis suffer from increased sensitivity to heat, also known as thermosensitivity. An increase in heat will often result in a worsening of symptoms such as fatigue, visual loss, spasticity, weakness and pain. The increase in heat can be due to external or internal factors. Externally, an increase in heat can result from an increased

[9] Davis, S, et al, 'Thermoregulation in multiple sclerosis', *Journal of Applied Physiology*, vol. 109, no.5, <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2980380/> accessed 3 October 2019, pp-1531-1537.
[10] Davis, Ibid.
[11] MS Australia, 'Heat sensitivity', 2017, https://www.msaustralia.org.au/publications/heat-sensitivity, accessed 10 October 2019.

environmental temperature. Internally, core temperature can increase because of a fever from an infection or during exercise that can also lead to symptoms of thermosensitivity[12].

McKenzie AAT Case ruling

In 2019 a high profile NDIS / AAT case ruled in favour of funding the replacement and upgrading of an air-conditioning system in the participant's home to assist with thermoregulation associated with their Multiple Sclerosis. To support the case, Dr Ollie Jay from the Faculty of Health Sciences, University of Sydney, provided a report titled 'Air conditioning for people with multiple sclerosis – is it reasonable and necessary support under the NDIS?'

While the report was specific to the participant's circumstances, the report found that broadly "Heat intolerance for people with MS is a phenomenon where individuals will experience a temporary worsening of their symptoms and a rapid onset of fatigue during exercise or with exposure to arm/hot environments. An intolerance to heat supposedly occurs when an individual has an increase in core temperature of 0.2 to 0.5c, irrespective of a person's thermoregulatory needs. There is a strong argument supporting the efficacy of air conditioning use for reducing the severity and frequency of symptoms in heat sensitive MS people" (page 12 of report).

There is a quality research supporting the link between MS and thermoregulatory dysfunction and that many people with MS experience a worsening of symptoms when exposed to heat stressors.

Epidermolysis Bullosa (EB)

Heating and **Cooling**

- **Epidermolysis Bullosa Simplex:** The most common type, it first shows up in newborns. It mainly affects the palms of the hands and soles of the feet.
- **Junctional epidermolysis bullosa:** While it also first appears in babies, this is a more severe form that causes blistering in deep layers of the skin.
- **Dystrophic epidermolysis bullosa:** If you have this type, your skin doesn't have collagen to hold it together, or the collagen you do have doesn't work well. This means the layers of your skin don't seal together like they should. Sometimes this type doesn't show up until early childhood.
- **Kindler syndrome:** This is a mixed condition, since blisters appear across different skin layers. It can also cause patchy changes in your skin colouring when it's exposed to the sun.
- **Epidermolysis bullosa acquisita:** This form causes blisters on your hands and feet as well as in mucous membranes like the mouth[13].

EB has no cure or treatment. WebMD recommends that at home care to prevent blisters and care for skin is the best approach. One of these recommendations is to "Keep cool. Keep your bath water no warmer than room temperature. Stay in air conditioning as much as you can and avoid heat and humidity"[14].

Wounds International, have published 'best practice guidelines for skin and wound care in epidermolysis bullosa'. The guidelines state that "wounds that have almost healed are particularly pruritic and scratching can lead to wound breakdown. Apart from skin breakdown, intense pruritus

[12] DiCarrado, loc cit.
[13] WebMD, 'What is Epidermolysis Bullosa', 2019', https://www.webmd.com/skin-problems-and-treatments/epidermolysis-bullosa-what-is#1, accessed 10 October 2019.
[14] Ibid.

can be seen as part of the pain spectrum and can lead to insomnia and depression. Practical advice on patients experiencing pruritus is to:

- Avoid sudden changes in temperature and overheated environments where possible.
- Some patients may benefit from air conditioning, a Dyson fan which is non-buffering and Chillow pillows in the hotter months. This is a particular consideration in overheated hospital environments[15].

People with EB are extremely vulnerable to external trauma and environmental changes. Maintaining a stable environmental temperature will assist in the management of wounds.

Epilepsy – febrile seizures

Cooling

There are several scientific studies that have been conducted which support the link between some types of epilepsy and temperature induced seizures.

A study from 2017 examined heat induced temperature dysregulation and seizures in Dravets Syndrome and epilepsy with febrile seizures (FS) plus (GEFS+). The study found that:

- "It has been established that febrile seizures and its extended syndromes like generalized epilepsy with febrile seizures (FS) plus (GEFS+) and Dravets syndrome have been associated with mutations especially in *SCN1A* and *GABRG2* genes. In patients, the onset of FS is likely due to the combined effect of temperature and inflammation in genetically vulnerable individuals because fever is often associated with infection. . . We demonstrated age-dependent dysregulated temperature control and that temperature elevation produced myoclonic jerks, generalized tonic clonic seizures (GTCSs) and heightened anxiety-like symptoms in *Gabrg2*$^{+/Q390X}$ mice. The study indicated that regardless of other inflammatory factors, brief heat alone increased brain excitability and induced multiple types of seizures in *Gabrg2*$^{+/Q390X}$ mice, suggesting that mutations like *GABRG2 (Q390X)* may alter brain thermal regulation and precipitate seizures during temperature elevations"[16].

A study from 2012 conducted by the Department of Anatomy and Neurobiology at the University of California examined Drosophila (fruit fly used in genetic research) cellular mechanisms to mirror heat-induced seizures in human epilepsy[17]. Basically, through examining cellular sodium channel mutations common in people with genetic epilepsy with febrile seizures plus (GEFS+), the researchers were able the link to this mutation to central nervous system dysfunction causing febrile seizures[18].

A small study conducted in 2017 of two children with 'hot water epilepsy'. "Reflex epilepsies represent a form of epilepsy in which unique modes of seizure precipitation are characterized by

[15] Denyer J, Pillay E, Clapham J. Best practice guidelines for skin and wound care in epidermolysis bullosa. An International Consensus, Wounds International, 2017 <http://www.debra-international.org/fileadmin/media_data/4_DEBRA_International/CPGs/Guidelines/International_Consensus_Best_Practice_Guidelines_Skin_and_Wound_Care_in_Epidermolysis_Bullosa.pdf>, accessed 7 October 2019, p. 26.

[16] Warner, TA et al., 'Heat induced temperature dysregulation and seizures in Dravet Syndrome/GEFS+ Gabrg2+/Q390X mice', Epilepsy research, vol. 134, 2017, pp.1-8, https://www.sciencedirect.com/science/article/abs/pii/S0920121117302620, accessed 10 October 2019.

[17] Sun, L et al., 'A knock-in model of human epilepsy in Drosophila reveals a novel cellular mechanism associated with heat-induced seizure', Journal of Neuroscience, vol. 10, no. 32, 2012, pp. 14145-55, https://www.ncbi.nlm.nih.gov/pubmed/23055484, accessed 11 October 2019.

[18] Ibid.

endogenous or exogenous stimuli. Hot water epilepsy represents a subtype of reflex epilepsy in which seizure precipitation arises from the act of immersing the head with hot water"[19]. This study found a link between seizure precipitation and exiting water[20].

Dravet Syndrome

Cooling

Dravet syndrome (DS) is a severe form of epilepsy characterized by frequent, prolonged seizures often triggered by high body temperature (hyperthermia), developmental delay, speech impairment, ataxia, hypotonia, sleep disturbances, and other health problems. Hyperthermia, or overheating, is a common seizure trigger in Dravet Syndrome, and patients display heightened sensitivity to warm baths, fevers, exertion, and other forms of temperature elevation[21].

The Epilepsy Queensland website notes that: "Seizures in Dravet syndrome can be increased by heat (hot days, hot showers or exercise) and in some (not all) children by visual stimulation (flickering lights or patterns)"[22].

People with epilepsy or Dravet syndrome may experience heat induced seizures and are at risk in elevated temperatures.

Parkinson's disease

Cooling

Mayo clinic defines Parkinson's disease as "a progressive neurological disease that affects movement. Symptoms include tremors, slowed movement (bradykinesia), rigid muscles, impaired posture and balance, loss of automatic movement, speech and writing changes. Other symptoms can include cognitive difficulties, emotional changes, swallowing difficulties and eating problems, sleep problems and disorders, bladder issues and constipation. Also blood pressure changes, smell dysfunction, fatigue, pain and sexual dysfunction"[23].

There are a variety of publications examining the link between thermoregulation and Parkinson's disease:

Mayo states that

- "Autonomic dysfunction in Parkinson's disease encompasses thermoregulatory symptoms. Research has demonstrated "deficits of sweating and vasomotor tone which often correlate with the severity of other autonomic deficits. Tests of thermoregulatory function can also be used to differentiate Parkinson disease from other neurodegenerative disorders. The pathophysiology of thermoregulatory dysfunction in Parkinson disease encompasses both central and peripheral mechanisms; involvement of the brainstem and hypothalamus with alpha-synuclein pathology is well recognised with increasing evidence of peripheral neuropathy in Parkinson disease that influences thermoregulation. Medications used to treat Parkinson's disease also affect thermoregulatory symptoms. Disorders of

[19] Appuvu, B et al., 'Seizures Induced by Exiting Water: A Unique Form of Reflex Epilepsy', Neurologist, vol. 22, no. 5, 2017, pp. 196-198, https://www.ncbi.nlm.nih.gov/pubmed/28859025, accessed 14 October 2019.
[20] Ibid.
[21] National Organization for Rare Disorders, 'Dravet Syndrome', 2018, https://rarediseases.org/rare-diseases/dravet-syndrome-spectrum/, accessed 11 October 2019.
[22] Epilepsy Queensland, 'Dravet syndrome', 2013, https://www.epilepsyqueensland.com.au/dravet-syndrome, accessed 11 October 2019.
[23] Mayo Clinic, 'Parkinson's disease', 2019, https://www.mayoclinic.org/diseases-conditions/parkinsons-disease/symptoms-causes/syc-20376055, accessed 11 October 2019.

thermoregulation significantly affect the quality of life for patients and their caregivers and can be severe and even life threatening, such as in the parkinsonism-hyperpyrexia syndrome"[24].

A journal publication from 2012 examining thermoregulatory dysfunction in Parkinson's states that:

- "Homeotherms, such as humans with Parkinson's disease, must maintain core body temperature in a narrow range in the face of fluctuating environmental surroundings and endogenous heat production. A complex and highly integrated collection of autonomic, endocrine, and behavioral responses are involved in the maintenance of core temperature. Dopaminergic innervation of the preoptic and anterior hypothalamus plays an important role in the central nervous system's control of body temperature. Due to a combination of central dopamine deficiency and peripheral autonomic dysfunction, individuals with Parkinson's disease may experience heat and/or cold intolerance and paroxysmal hyperhidrosis. Sudomotor dysfunction in Parkinson's disease can be documented with the sympathetic skin response and quantitative sudomotor axon reflex and thermoregulatory sweat tests"[25]

A recent study from 2019 investigated the potential differences in the size and shape of the thalamus in Parkinson's disease, and how morphology and functional connectivity related to clinical variables. The data from this study demonstrated:

- "That Parkinson's disease is associated with increases in functional connectivity between motor subdivisions of the thalamus and the supplementary motor area, and between prefrontal thalamic subdivisions and nuclei of the basal ganglia, anterior and dorsolateral prefrontal cortices, as well as the anterior and paracingulate gyri. These results suggest that Parkinson's disease is associated with increased functional connectivity of subdivisions of the thalamus which may be indicative alterations to basal ganglia-thalaamocortical circuitry"[26].

In 1991 a study was conducted into sweating and vasodilator responses in 22 people with Parkinson's disease in order to evaluate the thermoregulatory function.

- "Sweating was evaluated on different areas of the body with a colorimetric method (Minor's method). The superficial vasodilatation at the level of the face was assessed after oral intake of nitroglycerin by means of telethermography. Sweating and superficial vasodilatation were reduced in parkinsonian patients compared with control subjects. Asymmetries in sweating and superficial vasodilator responses were also observed between the left and right sides of the body in the patients. The decreased heat elimination was more apparent on the symptomatic side in patients with hemiparkinsonism. No relationship was found between the alterations of the thermoregulation and the other clinical features of Parkinson's disease[27]".

In 2013 a study was published that explored the relationship between symptoms of rapid eye movement sleep behaviour disorder, thermoregulation and sleep in Parkinson's disease. The study

[24] Coon, E & Low, PA, 'Thermoregulation in Parkinson disease', Handbook of Clinical Neurology, 2018, Mayo Clinic, https://mayoclinic.pure.elsevier.com/en/publications/thermoregulation-in-parkinson-disease, accessed 11 October 2019.
[25] LeDoux, M, Thermoregulatory Dysfunction in Parkinson's disease', Current Clinical Neurology, 2012, pp.213-227, [abstract], https://link.springer.com/chapter/10.1007/978-1-60761-429-6_14, accessed 11 October 2019.
[26] Owens-Walton, C et al., 'Increased functional connectivity of thalamic subdivisions in patients with Parkinson's disease', PloS One, Vol. 4, No.14, 2019, https://www.ncbi.nlm.nih.gov/pubmed/31483847, accessed 16 October 2019.
[27] De Marinis, M, et al., 'Alternations of thermoregulation in Parkinson's Disease', Functional Neurology, vol.6 no.3, pp279-83, 1991, https://www.ncbi.nlm.nih.gov/pubmed/1743543, accessed 11 October 2019.

group comprised 12 patients with Parkinson's disease and 11 healthy age-matched controls. We investigated markers of thermoregulation (core-body temperature profile), circadian rhythm (locomotor actigraphy) and sleep (polysomnography)[28]. The key findings from this study were:

- "The mesor (the mean value around which the core temperature rhythm oscillates) of the core-body temperature in patients with Parkinson's disease was significantly lower than that of controls".
- "The brainstem pathology associated with disruption of thermoregulation in Parkinson's disease may also contribute to rapid eye movement sleep behavioural disorder. It is possible that detailed analysis of the core-body temperature profile in at risk populations such as those patients with idiopathic rapid eye movement sleep behaviour disorder might help identify those who are at high risk of transitioning to Parkinson's disease[29]".

People with Parkinson's disease often experience thermoregulatory dysfunction and may have difficulty with both heat and cold intolerance.

Fibromyalgia

Heating

Fibromyalgia (FM) is a condition in which people experience symptoms that include widespread pain and tenderness in the body, often accompanied by fatigue and problems with memory and concentration.

FM affects two to five per cent of the population, mainly women, although men and adolescents can also develop the condition. It tends to develop during middle adulthood.

The symptoms of FM can vary from mild to severe. The most common symptoms are:

- increased sensitivity to pain due to a decreased pain threshold
- increased responsiveness to sensory stimuli such as heat, cold, light, smell
- extreme fatigue (tiredness)
- problems with memory and concentration (fibro fog)
- problems with sleep[30].

A publication in a clinical pain journal from 2014 examined the overlap between thermoregulation and pain modulation in FM. The review summarises the literature describing commonalities between the regulation of pain and temperature that may contribute to the widespread pain of FM.

The research found that:

- "Fibromyalgia syndrome is characterized by widespread pain that is exacerbated by cold and stress but relieved by warmth. We review the points along thermal and pain pathways where temperature may influence pain. We also present evidence addressing the possibility that brown adipose tissue activity is linked to the pain of FM given that cold initiates

[28] Zhong, G, et al., 'The Relationship between Thermoregulation and REM Sleep Behaviour Disorder in Parkinson's Disease', PLoS One, 2013, https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0072661
[29] Ibid.
[30] Better Health Channel, 'Fibromyalgia', 2017, https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/fibromyalgia, accessed 11 October 2019.

thermogenesis in brown adipose tissue via adrenergic activity, while warmth suspends thermogenesis"[31].

- Both FM and thermoregulation are exquisitely sensitive to stress. Acute cold and stress increase the generation of heat by increasing UCP1 activity in Brown Adipose Tissue (BAT) while chronically high sympathetic tone increases the synthesis of UCP1, increasing BAT volume (adaptive thermogenesis) to guard against persistent stress. The high sympathetic tone in patients with FM aggravates their pain and should initiate adaptive thermogenesis, yet their temperature is lower than healthy individuals. This indicates either insufficient heat production or enhanced heat loss, the latter being unlikely as sympathetic tone tends to curb heat loss. [and] Exercise may relieve symptoms of FM and improve thermoregulation by gradually decreasing adrenergic activity and providing an alternate source of body heat[32].

As thermogenesis (the production of heat) and associated pain is the more common concern for people with FM, requests for heating (via split system) may be more common than requests for air conditioning.

A study from 2015 investigated potential dysfunctions of the Autonomic Nervous System (ANS) in FM patients through the measurement of the autonomic response during a cold-water test. In the study, 23 female patients with FM and 15 healthy female controls were recruited. First, FM patients filled out the following questionnaires: PainDETECT, American College of Rheumatology (ACR) criteria of FM, and Profile of Mood States (POMS). Healthy controls only filled out the POMS. Subsequently, all participants immersed their forearm into 1 degrees C cold-water as long as they could tolerate for a maximum of 120 seconds. A thermographic camera recorded skin temperature and its recuperation process.

The research concluded that:

- The two groups differed significantly regarding central body temperature, forearm thermography, and peripheral (forearm)-central (ear) temperature ratio. FM patients showed less tolerance to cold water than control participants. Although total temperature decrease, cool-down rate, recuperation between 0 and 20 minutes after withdrawal showed significant intergroup differences, thermal recovery followed similar patterns in both groups.
- Peculiar ANS baseline characteristics are seen in FM patients. Although those patients have reduced ability to sustain low temperatures, therefore limiting extrapolation of inter-group analysis, their thermal-adaptive responses were found different as compared to controls.

People with fibromyalgia commonly experience increased pain brought on by exposure to cold temperatures and an apparent autonomic dysfunction in regulating thermal adaptive processes.

Muscular Dystrophy

Heating and cooling

Muscular dystrophy is the name given to a group of inherited neuromuscular conditions. These conditions cause weakness and wasting of the muscles. This muscle wastage gets worse over time, and is not reversible.

[31] Larson, AA et al., 'Review of overlap between thermoregulation and pain modulation in fibromyalgia', Clinical Journal Pain, vol. 30, no. 6, 2014, pp.544-555, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3864605/, accessed 15 October 2019.
[32] Ibid.

There are more than 30 different types of muscular dystrophy. Most are caused by changes to genes involved in providing strength to the muscle structure[33].

Many of the conditions that fall under 'muscular dystrophy' list impaired pain and temperature sensation as a common symptom[34].

Some people with Muscular dystrophy experience difficulty in relaxing muscles in cold temperatures[35].

Muscular Dystrophy UK have published an Adaptation Manual: for children and adults with muscle wasting conditions which is endorsed by the College of Occupational Therapists UK. The manual acknowledges that:

- For people with muscle wasting conditions, and their inevitable lack of mobility, it is essential to provide higher than average levels of heating. This is especially important for the bedroom, bathroom and living room areas.
- Heating is particularly important in the bathroom, especially where it has more than one external wall. Without adequate heating, it is likely the bathroom will not be used.
- Most children with muscle-wasting conditions feel the cold from a very young age. As their conditions progress and their mobility decreases, the problem becomes more severe. This is common to people of all ages with similar muscle-wasting conditions.
- When planning an adaptation that requires an extension, it's important to ensure the boiler has the capacity to heat the new rooms and contain sufficient water.
- A wall-mounted heater should be installed in the bathroom to provide supplementary heating in the winter and in the summer when the central heating is not required.
- Where there is medical need, it may be possible to grant-fund the installation of a new central heating system, or the extension of an existing one, if necessary with an upgraded boiler. The grant may not cover the cost of installing radiators in rooms that are either inaccessible to the disabled person or not used by them.
- It is also important to stress that the type of heating system chosen must be instantly controllable and therefore capable of being boosted when necessary and able to provide a constant temperature and be suitable to be left on, when the disabled person is out of the house.
- Storage heaters are not adequate because the temperature must remain constant over any 24-hour period. Also, individual radiant electric heaters are not suitable, because many people would hesitate to leave them unattended. In no circumstances should the disabled person return to an unheated house.
- Consider carefully the type of control and its location so that it can be operated safely and easily by the user. With the advances in technology, there is now the potential to operate

[33] Better Health Channel, 'Muscular Dystrophy', 2019, https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/muscular-dystrophy, accessed 17 October 2019.
[34] Muscular Dystrophy Foundation Australia, 'Facts about Myotonic Muscular Dystrophy', 2012, http://mdaustralia.org.au/wp-content/uploads/sites/4/2009/02/List-of-Neuromuscular-Conditions.pdf, accessed 17 October 2019.
[35] Muscular Dystrophy South Australia, 'List of Neuromuscular Conditions', 2009, http://mdaustralia.org.au/wp-content/uploads/2012/07/013_myotonic-dystrophy-2012.pdf, accessed 17 October 2019.

heating from smart phones and computers. These may be worth considering where an individual may not be able to manage a fixed thermostatic control[36].

For people with muscular dystrophy will commonly experience heightened sensitivity to cold, so maintaining a warm external environment is essential.

Scleroderma

Heating

Scleroderma as an autoimmune condition. Arthritis Australia writes that

- "Scleroderma affects the connective tissues of the body (tissues that hold together joints, muscles, blood vessels and internal organs). The connective tissues of people with scleroderma have too much of a protein called collagen. Collagen is important to give connective tissue its strength, but excess collagen causes hardening and tightening of the affected area. There are two major types of scleroderma:
    - Localised scleroderma (sometimes called 'morphea'). This form of scleroderma affects only the skin and sometimes the tissues beneath it (for example, muscle). This can lead to stiffness and difficulties moving the joints in the affected areas.
    - Systemic sclerosis. This form affects the connective tissue throughout the body, including blood vessels, joints, the digestive system (oesophagus, stomach and bowel), and occasionally the lungs, heart, kidneys and muscles[37].

A common symptom of Scleroderma is Raynaud's phenomenon where "The fingers or toes turn white, then blue in the cold, and then red as blood flow returns. This is caused by narrowing of the blood vessels, in response to cold weather. It is possible to have Raynaud's without having scleroderma, but most people with scleroderma will have symptoms of Raynaud's at some time and it is often one of the first symptoms to appear"[38]. Arthritis Australia recommend the best way to manage Raynaud's phenomenon is to "Minimise exposure to cold and sudden temperature changes. Make sure your whole body is kept warm and protect your hands and feet with gloves and warm socks. Avoid cigarette smoke"[39].

Better Health Channel Victoria write that Raynaud's phenomenon is the short-term interruption of blood flow to the extremities, such as the fingers and toes and suggest the best way to treat Raynaud's is to control environmental factors and avoid prolonged exposure to cold weather[40].

Mayo Clinic recommend the best way to prevent Raynaud's attacks are to:

To help prevent Raynaud's attacks:

- **"Bundle up outdoors.** When it's cold, don a hat, scarf, socks and boots, and two layers of mittens or gloves before you go outside. Wear a coat with snug cuffs to go around your mittens or gloves, to prevent cold air from reaching your hands.

[36] Muscular Dystrophy UK, 'Adaptations Manual: for children and adults with muscle wasting conditons', second edition, 2017, http://www.musculardystrophyuk.org/wp-content/uploads/2017/04/INF23-A---Adapt-web.pdf, accessed 11 October 2019.
[37] Arthritis Australia, 'Scleroderma', 2017, https://arthritisaustralia.com.au/types-of-arthritis/scleroderma/, accessed 17 October 2019.
[38] Ibid.
[39] Ibid.
[40] Better Health Channel, 'Raynaud's phenomenon', 2019, https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/raynauds-phenomenon, accessed 17 October 2019.

- Use chemical hand warmers. Wear earmuffs and a face mask if the tip of your nose and your earlobes are sensitive to cold.
- **Warm your car.** Run your car heater for a few minutes before driving in cold weather.
- **Take precautions indoors.** Wear socks. When taking food out of the refrigerator or freezer, wear gloves, mittens or oven mitts. Some people find it helpful to wear mittens and socks to bed during winter.
- **Because air conditioning can trigger attacks, set your air conditioner to a warmer temperature**. Use insulated drinking glasses"[41].

People with Scleroderma / Raynaud's phenomenon will likely experience a sensitivity to cold environmental temperatures.

Systemic Lupus Erythematosus (SLE)

Heating and Humidifiers

Systemic lupus erythematosus (SLE), otherwise known as lupus, is a chronic condition that results from a malfunctioning immune system. The immune system is designed to identify foreign bodies (such as bacteria and viruses) and attack them to keep us healthy. However in the case of lupus, your immune system mistakenly attacks healthy tissue, causing inflammation in parts of the body such as the skin, joints, kidneys, heart and lungs[42].

Diagnosis of SLE can be challenging, but is based on demonstration of a number of clinical manifestations as well as immunological abnormalities. Referral to a rheumatologist is strongly recommended to assist with the diagnosis and make treatment recommendations. Management of SLE depends on the level of disease activity and can include general measures, NSAIDs and steroids. Immunosuppression is often required and specific targeted therapy is on the horizon[43].

The goal of treatment is remission or control of disease activity and prevention of (further) organ damage with the minimum possible dose of glucocorticoids. Treatment with the drugs available can clearly improve the short- and long-term prognosis of SLE. A modern treatment strategy should comprise not only preventive measures but also the treatment of comorbidities (e.g., infections and cardiovascular events)[44].

Approximately one third of people with Lupus experience Raynaud's phenomenon (as discussed in Scleroderma)[45]. Another condition that commonly overlaps with Lupus is Sjorgen's syndrome, which "affects the body's ability to produce moisture in the glands of the eyes, nose, mouth, and vagina"[46]. People with Sjorgen's syndrome are recommended to keep a high-humidity work and home environment to control moisture.

[41] Mayo Clinic, 'Raynaud's disease', 2019, https://www.mayoclinic.org/diseases-conditions/raynauds-disease/symptoms-causes/syc-20363571, accessed 17 October 2019.
[42] Better Health Channel, 'Lupus', 2019, https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/lupus, accessed 17 October 2019.
[43] Apostolopoulos, D & Yik-Bun Hoi, A, 'Systemic lupus erythematosus', Royal Australian College of General Practitioners', 2013, https://www.racgp.org.au/afp/2013/october/systemic-lupus-erythmatosus/, accessed 11 October 2019.
[44] Kuhn, A et al., 'The Diagnosis and Treatment of Systemic Lupus Erythermatosus', Deutches Arzteblatt, vol 112, no. 25, 2015, pp-423-432, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4558874 /
[45] Lupus Foundation of America, 'About Raynaud's Disease', 2015, https://www.lupus.org/resources/about-raynauds-disease, accessed 16 October 2019.
[46] Ibid.

A study from 2009 found that there was a significant link between Lupus and thyroid dysfunction. The study found that "Our patients with SLE had a high prevalence of symptomatic and significantly more subclinical hypothyroidism and positive thyroid autoantibodies. Thyroid autoantibodies may precede the appearance of clinical autoimmune disease. Sjögren syndrome and positive rheumatoid factors were more frequently observed in SLE patients with autoimmune thyroid disease. We believe that, since symptoms of SLE and thyroid disease can be similar, that SLE patients should routinely been investigated for autoimmune thyroid disease"[47].

The hypothalamus-pituitary-thyroid glands are the organs involved in *thermoregulation* (If the thyroid hormone level is too low, the hypothalamus sends out more thyrotropin-releasing factor (TRF) and if it is too high it sends out less. If the thyroid hormone level is too low, the pituitary sends out more thyroid-stimulating hormone (TSH) and if it is too high it sends out less).

This common comorbidity between Lupus, thyroid dysfunction and Raynaud's phenomenon may be the reason that Lupus made it onto the South Australia medical heating and cooling concession list. If a participant has either of these common comorbidities they will likely have difficulty with thermoregulation. This may be with both heating and cooling.

Motor Neurone Disease

Heating and **Cooling**

Motor neurone disease (MND) is also called amyotrophic lateral sclerosis (ALS) and Lou Gehrig's disease. It is a rapidly progressing, neurological disease. MND often begins with weakness of the muscles in the hands, feet or voice, although it can start in different areas of the body and progress in different patterns and at different rates. People with MND become increasingly disabled. Life expectancy after diagnosis is one to five years, with 10 per cent of people with MND living 10 years or more. The needs of people with MND are complex and vary from person to person[48].

Better Health Channel (Vic) writes that common symptoms of MND are insomnia, breathlessness, coldness and swelling, which all can be assisted by controlling the environmental temperature[49].

A journal publication from 2018 reviewed the evidence linking Amyotrophic lateral sclerosis (ALS) and thermoregulation. This review concluded that "while ALS is not classically associated with defective thermoregulatory function, its progression severely affects key brain regions controlling body temperature and impacts multiple sensors and effectors of this homeostatic function. Furthermore, animal models of ALS display disturbed thermoregulation as a consequence of disrupted energy homeostasis. All these lines of indirect evidence call for studies directly addressing the body temperature regulatory system, both as a potential biomarker and as a possible modifier of disease progression in ALS[50].

Another publication from 2002 measured the sweat loss of ALS patients with MND against a control group and found that MND is linked to Sudomotor dysfunction (sudomotor is anything that stimulated the sweat glands). The study found that Autonomic dysregulation is part of the complex degenerative process in amyotrophic lateral sclerosis (ALS). In early ALS, patients had significantly higher skin water loss than control subjects over the thenar (rounded fleshy part of hand at base of

[47] Appenzeler, S, 'Prevalence of thyroid dysfunction in systemic lupus erythematosus', Jounral of Clinical Rheumatology, vol. 15 no. 3, 2009, pp.117-19, https://www.ncbi.nlm.nih.gov/pubmed/19300286
[48] Better Health Channel, 'Motor Neurone Disease', 2018, https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/motor-neurone-disease, accessed 11 October 2019.
[49] Ibid.
[50] Dupius, L et al., ' Thermoregulation in amyotrophic leteral sclerosis', Handbook of Clinical Neurology, vol. 157, 2018, pp. 749-760, https://www.ncbi.nlm.nih.gov/pubmed/30459038, accessed 17 October 2019.

thumb) and the hypothenar (fleshy part of palm) eminences. In advanced disease stages, sweating was decreased at all sites compared with controls. A significant decline in sweat secretion of about 40% was found over a six month period. The findings suggest an abnormal sympathetic activity with hyperhidrosis in early ALS and a reduction in sweat production as the disease progresses[51].

Some people with MND will experience difficulty in regulating body temperature in response to environmental factors, particularly in sweat production.

Post-Polio syndrome/Poliomyelitis

Heating

The National Institute of Neurological Disorders and Stroke define Post-polio syndrome (PPS) as a

- "Condition that can strike polio survivors decades after their recovery from poliomyelitis. Polio is an acute viral disease that destroys motor neurons. Many people who are affected early in life recover and develop new symptoms many decades later. After acute polio, the surviving motor neurons expand the amount of muscle that each controls. PPS and Post-Polio Muscular Atrophy (PPMA) are thought to occur when the surviving motor neurons are lost in the aging process or through injury or illness. Many scientists believe PPS is latent weakness among muscles previously affected by poliomyelitis and not a new MND".
- "Symptoms include fatigue, slowly progressive muscle weakness, muscle atrophy, fasciculations, cold intolerance, and muscle and joint pain. These symptoms appear most often among muscle groups affected by the initial disease, and may consist of difficulty breathing, swallowing, or sleeping. Other symptoms of PPS may be caused by skeletal deformities such as long-standing scoliosis that led to chronic changes in the biomechanics of the joints and spine. Symptoms are more frequent among older people and those individuals most severely affected by the earlier disease. Some individuals experience only minor symptoms, while others develop muscle atrophy that may be mistaken for ALS. PPS is not usually life threatening. Doctors estimate that 25 to 50 percent of survivors of paralytic poliomyelitis usually develop PPS[52].

A study from 2012 examining the effects of a traditional Chinese therapy practice in post-polio syndrome patients with cold intolerance cites another Brazilian study from 2006 (could not access 2006 study). The 2006 study found that:

- "167 patients who had previously been diagnosed with paralytic poliomyelitis and subsequently with PPS highlighted a CI frequency of 69.8%". The study found that "The affected extremities are often unseasonably cold due to involvement of the sympathetic nerve cells, leading to vasoconstriction"[53].

[51] Beck, M et al., 'Progressive sudomotor dysfunction in amyotrophic lateral sclerosis', Journal of Neurology, Neurosurgery and Psychiatry, vol. 73, 2002, pp.68-70, https://www.ncbi.nlm.nih.gov/pubmed/12082050, accessed 15 October 2019.

[52] National Institute of Neurological Disorders and Stroke, 'Motor Neurone Diseases Fact Sheet', 2019, https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Motor-Neuron-Diseases-Fact-Sheet, accessed 15 October 2019.

[53] Quadros, AAJ & Oliveira ASB, Síndrome pós-poliomielite (SPP): avaliação de 167 pacientes, 2006, in Ramos, PE, 'Effects of Dăoyĭn Qigōng in postpolio syndrome patients with cold intolerance', Arquivos de Neuro-Psiquiatria, vol.70 no.9, Sept. 2012, <http://dx.doi.org/10.1590/S0004-282X2012000900006>, accessed 16 October 2019.

Participants with post-polio will likely experience cold intolerance, however it is unclear if the severity of this cold intolerance would be reasonable or necessary. Additional clothing would likely be just as effective.

Lymphoedema (>Grade 1)

Cooling

Lymphoedema is listed as a qualifying condition for three of the state and territory heating and cooling subsidy schemes. Lymphoedema is the accumulation of excessive amounts of protein-rich fluid resulting in swelling of one or more regions of the body.

This is due to a mechanical failure of the lymphatic system and occurs when the demand for lymphatic drainage exceeds the capacity of the lymphatic circulation. The condition usually affects the limb(s) although it may also involve the trunk, breast, head and neck or genital area.

Whether primary or secondary, lymphoedema develops in stages, from mild to severe. Methods of staging are numerous and inconsistent. They ranged from three to as many as eight stages. In Australasia, the most commonly used stage scale is that adopted by The International Society of Lymphology (ISL) (3), which identifies the following stages:

- Stage 0 A latent or subclinical state where swelling is not evident despite impaired lymph transport.
- Stage I This represents early onset of the condition where there is an accumulation of tissue fluid with higher protein content, which subsides with limb elevation. The oedema may be pitting at this stage.
- Stage II Limb elevation alone rarely reduces swelling and pitting is manifest. In later Stage II the limb may or may not pit as fat and fibrosis supervenes.
- Stage III The tissue is hard (fibrotic) and pitting is absent. Skin changes such as thickening, hyperpigmentation, increased skin folds, fat deposits and warty overgrowth develop.
- Stage III encompasses lymphostatic elephantiasis. At this stage, the swelling is spontaneously irreversible and usually the limb(s) is very large[54].

The Cancer Council Australia website recommends to avoid putting pressure on the affected area to "keep cool in summer as the heat may make swelling worse – have cold showers, stay indoors during the hottest part of the day and drink plenty of water"[55].

While avoiding heat induced swelling is a standard lymphoedema management recommendation, it is unclear if NDIS funding for air conditioning would meet R & N legislative requirements for this cohort as there are more appropriate, lower cost management options.

Familial disautonomia (a genetic disorder affecting individuals' automatic (involuntary) bodily responses

Heating and **cooling**

[54] Australasian Lymphology Association, 'What is Lymphoedema?', 2019, https://www.lymphoedema.org.au/about-lymphoedema/what-is-lymphoedema/, accessed 11 October 2019.
[55] Cancer Council Australia, 'Lymphoedema treatment and management', 2015, https://www.cancercouncil.com.au/cancer-information/managing-cancer-side-effects/lymphoedema/treatment-and-management/ , accessed 17 October 2019.

The US National library of Medicine defines Familial dysautonomia as "a genetic disorder that affects the development and survival of certain nerve cells. The disorder disturbs cells in the autonomic nervous system, which controls involuntary actions such as digestion, breathing, production of tears, and the regulation of blood pressure and body temperature. It also affects the sensory nervous system, which controls activities related to the senses, such as taste and the perception of pain, heat, and cold. Familial dysautonomia is also called hereditary sensory and autonomic neuropathy, type III"[56].

The Familial Dysautonomia Foundation website lists common features of the condition as Unstable blood pressure and body temperature and 'Autonomic crises:' Episodes of cyclical vomiting accompanied by extremely high blood pressure and increased heart rate, sweating and fever"[57].

As Familial disautonomia is a condition impacting the autonomic nervous system, it is likely that participant's with this condition will experience thermoregulation issues.

Complex Regional Pain Syndrome

Heating and **cooling**

Pain Australia define Complex Regional Pain Syndrome (CRPS) as "a chronic nerve pain condition that usually affects the arms, legs, hands or feet. CRPS can occur after injury or trauma and is believed to be caused by damage to, or malfunction of, the nervous system. People with CRPS may experience any or all of the following symptoms: burning or "pins and needles" sensations; constant or intermittent changes in temperature and skin colour; swelling of the affected limb; loss of fine motor control; tremors or spasms; or stiffness. CRPS used to be known as Reflex Sympathetic Dystrophy (RSD)"[58].

The National Institute of Neurological Disorders and Stroke writes that "People with CRPS also experience changes in skin temperature, skin color, or swelling of the affected limb. This is due to abnormal microcirculation caused by damage to the nerves controlling blood flow and temperature. As a result, an affected arm or leg may feel warmer or cooler compared to the opposite limb. The skin on the affected limb may change color, becoming blotchy, blue, purple, pale, or red... [this means that another common feature of CPRS is] abnormal sweating pattern in the affected area"[59].

A study from 2006 studied 12 patients in whom CRPS type 1 through applying heat and cooling to the patient's hands and using videothermography to measure the response. The study found that patients with CRPS did have a level temperature regulation dysfunction and that the sympathetic efferent system is involved in CRPS[60]. Efferent neurons carry nerve impulses from the central nervous system to the muscles.

[56] US National Library of Medicine, 'Familial dysautonomia', 2019, https://ghr.nlm.nih.gov/condition/familial-dysautonomia, accessed 17 October 2019.
[57] Familial Dysautonomia Foundation, 'About FD', 2018, https://familialdysautonomia.org/about-fd
[58] Pain Australia, 'Complex regional pain syndrome', https://www.painaustralia.org.au/about-pain/forms-of-pain/complex-regional-pain-syndrome, accessed 11 October 2019.
[59] National institute of Neurological Disorders and Stroke, 2019, https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Fact-Sheets/Complex-Regional-Pain-Syndrome-Fact-Sheet, accessed 16 October 2019.
[60] Niehof, SP, 'Thermography imaging during static and controlled thermoregulation in complex regional pain syndrome type 1: diagnostic value and involvement of the central sympathetic system', vol. 5, no. 30, 2006, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1479347/, accessed 17 October 2019.

For participants who have complex regional pain syndrome, they will likely experience some degree of temperature regulation dysfunction making them vulnerable to changes in external temperature.

Stroke / Acquired Brain Injury

Cooling or heating

The Better Health Channel (VIC) discusses how ABI affects a person and states that "The long-term effects of brain injury are difficult to predict. They will be different for each person and can range from mild to profound. It is common for many people with ABI to experience increased fatigue (mental and physical) and some slowing down in how fast they can process information, plan and solve problems. They may experience changes to their behaviour and personality, physical and sensory abilities, or thinking and learning"[61].

Johns Hopkins Medicine[62] and the Healthline[63] website both state that damage to specific parts of the brain can affect the body's ability to regulate temperature.

A 2018 publication in the Handbook of Clinical Neurology discusses thermoregulation dysfunction in brain injury patients. This study found that;

- "Different mechanisms explain thermoregulatory dysfunction following ischemic stroke, hemorrhagic stroke, and traumatic brain injury. Temperature instability following brain injury likely involves hypothalamic injury, pathologic changes in cerebral blood flow, metabolic derangement, and a neurogenic inflammatory response"[64].

A cross-sectional study from 2017 examined "100 patients with ischemic or hemorrhagic stroke sequelae with unilateral hemiparesis and thirty healthy subjects. Individuals with nervous peripheral lesions, diabetes, peripheral vascular diseases or tumors were not included in this study. The volunteers underwent axillary temperature evaluations with the use of a cutaneous thermometer and evaluations of cutaneous temperature of hands and feet as measured by infrared thermography captured by an infrared sensor (ThermaCAMTM SC 500-FLIR Systems). The mean temperature (°C) was analysed". The study concluded that the Healthy individuals that were part of the study had "temperature symmetry between sides of the body, while individuals with stroke sequelae present lower temperature in the paretic side, especially on their feet"[65].

There is also a substantial amount of research and patient studies examining the immediate onset of fever in the acute period post-stroke. For example, "subarachnoid haemorrhage, cerebral trauma, along with ischaemic or haemorrhagic stroke are strongly associated with the development of central fever"[66].

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[61] Better Heath Channel, 'Acquired Brain injury', 2014, https://www.betterhealth.vic.gov.au/health/conditionsandtreatments/acquired-brain-injury, accessed 16 October 2019.
[62] Johns Hopkins Medicine, 'Effects on Stroke', 2019, https://www.hopkinsmedicine.org/health/conditions-and-diseases/stroke/effects-of-stroke, accessed 15 October 2019
[63] Healthline, 'The effects of Stroke on the Body', 2017, https://www.healthline.com/health/stroke/effects-on-body#1, accessed 15 October 2019.
[64] Gowda, R et al., 'Thermoregulation in brain injury', in Handbook of Clinical Neurology, vol. 157, no. 2018, pp. 787-797, https://www.sciencedirect.com/science/article/pii/B9780444640741000495, accessed 17 October 2019.
[65] Alfieri, FM et al., 'Evaluation of body temperature in individuals with stroke', Neuro Rehabilitation, vol. 40, no. 1, 2017, pp. 119-128, https://www.ncbi.nlm.nih.gov/pubmed/27935558, accessed 16 October 2019.
[66] Zawadska, M ' Thermoregulation disorders of central origin - how to diagnose and treat', Anaeasthiology Intensive Therapy, vol. 49, no. 3, 2017, pp.227-234, https://www.ncbi.nlm.nih.gov/pubmed/28803441, accesed 17 October 2019.

For participants who have had a stroke or acquired a brain injury that has resulted in thermoregulatory dysfunction, would be vulnerable to changes in external temperature.

ASD

Heating or **cooling**

The DSM-5 listing for Autism Spectrum Disorder Diagnostic Criteria lists the following:

> B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):
>
> > 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., **apparent indifference to pain/temperature**, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

The Raising Children website writes that some children with autism spectrum disorder commonly have sensitivities (hyposensitive or hypersensitive) to environmental stimuli such as noise, light, clothing or temperature[67]. As an example for temperature under sensitivity, a child might want to wear warm clothes in summer heat, or not feel the cold and wear shorts in winter.

The Mayo Clinic website, AutismNT and Better Health Channel websites all provide similar information about ASD and sensory issues.

While there is substantial evidence to support the link between ASD and sensory issues regarding temperature, there is little evidence to support air-conditioning or heating to be an effective and beneficial disability related health support. It is likely that heating or cooling related supports would only meet R & N for participants whose hyposensitivity or hypersensitivity to temperature was so significant that it placed the participant at risk.

Cerebral Palsy

Heating or **cooling**

When searching for information on cerebral palsy and thermoregulation or temperature sensitivities very little information came up. A few blogs and personal testimonies for assisting your child with CP in summer were available, but no published quality studies.

However, there is a substantial amount of information indicating that people with CP may experience disturbances in homeostatic functions resulting in autonomic dysfunction / neuropathy. However, a 2017 publication in the Journal for Developmental Medicine and Child Neurology provided a short summary of the research into the link between CP and autonomic dysfunction and concluded that while the link is well known, there is a surprising lack of methodologically sound cohort studies to support it[68].

[67] Raising Children Website, 'Sensory Sensitivities: children and teenagers with autism spectrum disorder', 2017, https://raisingchildren.net.au/autism/behaviour/understanding-behaviour/sensory-sensitivities-asd, accessed 17 October 2019.
[68] Dan, B, 'Understanding the autonomic nervous system in cerebral palsy', editorial, Developmental Medicine & Child Neurology, 2017, https://www.onlinelibrary.wiley.com/doi/epdf/10.1111/dmcn.13440 , accessed 16 October 2019.

Mayo Clinic states that: "Autonomic neuropathy occurs when the nerves that control involuntary bodily functions are damaged. It can affect blood pressure, temperature control, digestion, bladder function and even sexual function. The nerve damage interferes with the messages sent between the brain and other organs and areas of the autonomic nervous system, such as the heart, blood vessels and sweat glands"[69]. Autonomic dysfunction often results in sweating abnormalities, making it difficult for people to regulate body temperature.

One study from 2011, published in the Journal of Oral Pathology and Medicine, studied saliva samples of ninety people with CP compared the saliva samples of their sibling volunteers with no neurological damage. The study found that the individuals with CP presented a significant reduction in salivary flow rate and increased protein concentrations compared to the control group, indicating autonomic dysfunction[70].

An electronic magazine 'Complex Child' which is written by parents of children with disabilities, published an article in 2010 'Autonomic Dysfunction in Children with Cerebral Palsy, Static Encephalopathy, and Similar Conditions'. Complex Child conducted a "survey for children with cerebral palsy and similar conditions to evaluate the frequency of autonomic symptoms and likely Autonomic Dysfunction"[71]. The survey found that "80% of children had some degree of difficulty regulating their body temperature, but only 26% ran a fever, became hypothermic, or had a life-threatening response to heat or cold"[72]. Other autonomic symptoms were recorded: 11% of the children were not able to sense external temperature and 33% experienced sweating issues.

While this study was not published in a high quality medical journal or endorsed by a specialist in the field, the person who conducted the study, Susan Argawal, is a humanities academic in the Chicago area so would be familiar with research methodologies.

It appears that while the thermoregulation link in CP is generally accepted, there is a significant lack of well-grounded research.

Fanconi Anemia

Heating or **cooling** depending on the person's complex healthcare circumstances.

The National Organization for Rare Disorders defines Fanconi anaemia (FA) as "a rare genetic disorder, in the category of inherited bone marrow failure syndromes. Half the patients are diagnosed prior to age 10, while about 10% are diagnosed as adults. Early diagnoses are facilitated in patients with birth defects, such as small size, abnormal thumbs and/or radial bones, skin pigmentation, small heads, small eyes, abnormal kidney structures, and cardiac and skeletal anomalies. The disorder is often associated with a progressive deficiency of all bone marrow production of blood cells, red blood cells, white blood cells, and platelets. Affected individuals have an increased risk of developing a cancer of blood-forming cells in the bone marrow called acute

[69] Mayo Clinic, 'Autonomic Neuropathy', 2019, https://www.mayoclinic.org/diseases-conditions/autonomic-neuropathy/symptoms-causes/syc-20369829, accessed 15 October 2019.
[70] Ferreira, MC, et al., 'Autonomic nervous system in individuals with cerebral palsy: a controlled study', Journal of Oral Pathology & Medicine, 2011, https://onlinelibrary.wiley.com/doi/abs/10.1111/j.1600-0714.2011.01008.x, accessed 15 October 2019.
[71] Agrawal, S, 'Autonomic Dysfunction in Children with Cerebral Palsy, Static Encephalopathy, and Similar Conditions', Complex Child E Magazine, 2010, http://www.articles.complexchild.com/june2010/00207.pdf, p. 6.
[72] Op cit., p.9.

myeloid leukaemia (AML), or tumors of the head, neck, skin, gastrointestinal system, or genital tract"[73].

The US National Library of Medicine list the common symptoms or abnormalities that people with FA experience:

- "More than half of people with Fanconi anaemia have physical abnormalities. These abnormalities can involve irregular skin coloring such as unusually light-colored skin (hypopigmentation) or café-au-lait spots, which are flat patches on the skin that are darker than the surrounding area. Other possible symptoms of Fanconi anemia include malformed thumbs or forearms and other skeletal problems including short stature; malformed or absent kidneys and other defects of the urinary tract; gastrointestinal abnormalities; heart defects; eye abnormalities such as small or abnormally shaped eyes; and malformed ears and hearing loss. People with this condition may have abnormal genitalia or malformations of the reproductive system. As a result, most affected males and about half of affected females cannot have biological children (are infertile). Additional signs and symptoms can include **abnormalities of the brain and spinal cord (central nervous system),** including increased fluid in the center of the brain (hydrocephalus) or an unusually small head size (microcephaly)"[74].

While there was no readily available information supporting the direct link between FA and thermoregulation or autonomic dysfunction, people with FA frequently have related disorders including: chromoscomal instability disorders, acquired plastic anaemia, Thrombocytopenia-absent radius (TAR) syndrome, Dyskeratosis congenita, also known as Zinsser-Cole-Engman syndrome, VACTERL association, Myelodysplastic syndromes (MDS) and Acute myeloid leukemia (AML)[75].

Endocrine problems are also common in people with FA. A literature review published in 2015 examined endocrine disorders in FA patients and found that "About 80% of children and adults with FA have at least one endocrine abnormality, including short stature, GH deficiency, abnormal glucose or insulin metabolism, dyslipidemia, hypothyroidism, pubertal delay, hypogonadism, or impaired fertility"[76]. Hypothyroidism is well known to impact on metabolic processes and result in poor ability to tolerate cold.

A participant with FA is likely to have a significantly complex combination of health and disability related care needs. A health related requirement for maintaining environmental temperature could arise from several health conditions.

Spina Bifida

There is no readily available evidence to support the link between Spina Bifida and an inability to regulate heat.

The TAT advice that was published relating to Spina Bifida and air-conditioning was for a participant with a complex combination of health conditions including: osteoarthritis, HIV, sarcoidosis of the lungs, type 2 diabetes resulting in liver, kidney and pancreas damage.

[73] National Organization for Rare Disorders, 'Fanconi Anemia', 2019, https://rarediseases.org/rare-diseases/fanconi-anemia/, accessed 17 October 2019.
[74] US National Library of Medicine, 'Fanconi anemia', 2019, https://ghr.nlm.nih.gov/condition/fanconi-anemia
[75] https://rarediseases.org/rare-diseases/fanconi-anemia/, accessed 17 October 2019.
[76] National Organization for Rare Disorders, 'Fanconi Anemia'.

Air Conditioning

Types of air conditioning systems

There are two main types of air conditioning products on the market:

1. Refrigerative products (using the vapour compression cycle)
2. Evaporative products[77].

Refrigerative Air Conditioning

Below are the types of refrigerative air conditioners available with average price ranges as at 2019[78].

Type	Description	Price Range
Split system	Condition the air in a single room by blowing in cold air and sucking out the heat. They consist of an indoor wall-mounted unit and an outdoor standalone compressor that dissipates the heat from the cooled area. Split systems are generally quieter than other systems as the compressor (the loudest component) is placed outside. However, these units are not powerful enough to cool an entire house.	$600 to $2,800
Reverse system	Can be used all year round as they can heat and cool a room. These systems are generally a little more expensive than pure cooling systems, but might be ideal for those living in temperamental climates.	$800 to $3,000
Portable	Designed for small areas. These units can be moved relatively easily and are readily available. The downside is that portable air conditioners have a limited range and will prove ineffective in larger areas.	$400 to $1,200 (with no installation costs)
Wall/Window	Less common but can still be relied on to cool medium to large areas. The unit inside the home conditions the air and pumps the hot air outside, through an outlet or hose. They are generally more powerful than portable air conditioners. The downside is that some run on outlet power, requiring cumbersome extension cords and the units themselves can be large and noisy. They can also be expensive to run due to the amount of power they use.	$400 to $1,200
Ducted	Uses ducts in the walls and ceiling to distribute conditioned air across an entire home, making it more efficient in cooling large areas than any other system available. This is usually how large establishments such as hospitals air condition their buildings.	$5,000 +

[77] Energy Rating, "Air Conditioners", [website], 2019. http://www.energyrating.gov.au/products/space-heating-and-cooling/air-conditioners, accessed 8 September 2019.
[78] Canstar, "Air Conditioner Reviews & Ratings", [website], 2019. https://www.canstarblue.com.au/appliances/air-conditioners, accessed 7 September 2019.

Evaporative Air Conditioning

Evaporative air conditioners rely on the evaporation of water to cool air and in doing so increase the humidity in the space being cooled. Because of this, these types of systems are effective in drier climates, but not other areas.

Unlike conventional air conditioners (which remove moisture from the cooled space and work best in a sealed room), evaporative air conditioners require a large volume of fresh air to pass through the house, so ventilation to allow internal air to escape is essential.

Evaporative air conditioners can also consume substantial volumes of water, which may be an issue to consider for homeowners. [79]

Evaporative coolers don't suit high humidity environments, such as QLD, NT and northern WA, but may be more suitable for southern, less humid Australian areas, like ACT, VIC, SA and TAS. [80]

Evaporative coolers typically range in price from around $100, going up to close to $400. [81]

Components in determining air conditioning selection

According to The Energy Rating Website (a joint initiative of Australian, State and Territory and New Zealand Governments), when considering purchasing a new air conditioner, the most important initial step is to select a suitably sized unit.

There are many different elements within the home that will impact on the size air conditioner required. These include (but are not limited to):

- Whether the purchaser looking to heat/cool a single room, a larger space or an entire home;
- Size of room/home (including ceiling height);
- External wall materials;
- Insulation levels; and
- How many windows in the area, their glazing, shading and orientation. [82]

Strength and Capacity

Canstar Blue, the consumer review and comparison website, give a general indication of the strength and type of air conditioning system best suited to room size, [83] and the average cost of air conditioners per kilowatt capacity [84].

[79] Energy Rating, "Evaporative Air Conditioners", [website], 2019. http://www.energyrating.gov.au/products/evaporative-air-conditioners, accessed 8 September 2019.
[80] Canstar, "Evaporative Coolers Buying Guide", [website], 2019. https://www.canstarblue.com.au/appliances/evaporative-coolers-guide, accessed 7 September 2019.
[81] ibid
[82] Energy Rating, "Air Conditioners", [website], 2019. http://www.energyrating.gov.au/products/space-heating-and-cooling/air-conditioners, accessed 8 September 2019.
[83] ibid
[84] Canstar, "A guide to air con sizes and costs", [website], 2019. https://www.canstarblue.com.au/appliances/guide-aircon-sizes-costs, accessed 7 September 2019.

Strength/Type per room size

Strength	Type	Room size Suitability
2kW – 4kW	Portable Small split system Window box	Small rooms (<20m²)
4kW – 6kW	Window box Split system	Medium rooms (20m² - 40m²)
6kW – 9kW	Split system	Large rooms (>40m²)

Average cost of air conditioners per kilowatt capacity

Kilowatt Capacity	Average Price
2.5kW	$500 to $1,000
3.5kW	$750 to $1,500
5-6kW	$1,000 to $1,800
7-8kW	$1,500 to $2,000

Energy Costs

Australian consumer advocacy group Choice, suggest that running costs for a medium-sized air conditioner ranges from around $400 to $550 a year.

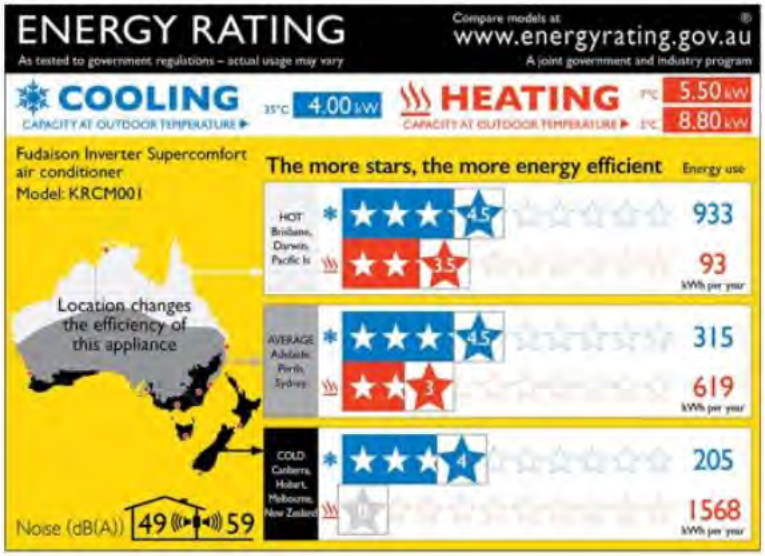
Choice measured running costs in their air conditioner reviews and determined that running costs can vary by a few hundred dollars a year, depending on the model[85]. They reviewed reverse-cycle split-system inverter air conditioners, ranging from small 2kW models suitable for a single bedroom, up to large models of 10kW or more, suitable for a large open-plan living area.

Size	Annual cost to run
Small (up to 4kW)	$242–$492
Medium (4–6kW)	$402–$552
Large (over 6kW)	$442–$586
Figures above are based on how much each model costs to deliver a set amount of cooling and heating per year at maximum capacity, with the remainder of the year in standby mode (based on electricity costs of 30 cents/kWh).	

[85] Choice, "How to buy the best air conditioner", [website], 2019. https://www.choice.com.au/home-and-living/cooling/air-conditioners/buying-guides/air-conditioners, accessed 7 September 2019.

Energy Ratings

In May 2019, energy rating labelling on air conditioners changed with the introduction of a new format label, showing how climate affects the energy efficiency of these appliances. The new air conditioner label indicates the difference in energy efficiency, depending on which of the three climate zones – hot, average or cold - in which it is used. The climate zone performance information helps consumers to purchase air conditioners best suited for their location.



Selection

In selecting the appropriate air conditioning type there are various factors which need to be considered. Considering the above information, a potential checklist might look like the following:

1. **GEOGRAPHIC REGION**: Identify the region using the Climate Zone Rating developed by the E3[86], which will give an indication of the type of air conditioning suitable.
2. **SPACE SIZE**: Determine the size of space which requires conditioning, which will give an indication of the strength and therefore type of air conditioner suitable.
3. **BUILDING MATERIALS:** Determine external wall materials (e.g. extent of glazing) and insulation levels of the home, which will give an indication of strength and therefore type of air conditioner suitable.
4. Select product.

[86] Equipment Energy Efficiency (E3) program is a cross jurisdictional program through which the Australian Government, states and territories and the New Zealand Government collaborate to deliver a single, integrated program on energy efficiency standards and energy labelling for equipment and appliances.

Cost and availability of Cooling Garments

There are several retail outlets in Australia for the purchase of cooling garments. The most prominent/popular garment appears to be the cooling vest. Cooling garments are promoted/marketed to those not just with a disability e.g. MS and spinal cord injury, but also to sports people/athletes, and outdoor workers. The market focus to disability is mainly directed to those with MS and Spinal Cord Injury.

Below is a table indicating the garment range and cost ranges sourced and collated from seven retail outlets in Australia.

Garment	Price Range	Notes
Vest	$138 - $470	Includes men's and women's sizes and styles.
Neck Tie	$17 - $20	
Neck Wrap	$30 - $40	
Cap	$60 - $70	
Cap – Skull	$22 - $25	
Quilts/Blankets	$60 - $150	Small to extra-large sizes
Towels	$50 - $72	

Literature Review - Cooling Garments

A literature review was carried out on the efficacy of cooling garments **(See Appendix B for full summary).**

A search for literature was carried out on the disability types in relation to thermoregulation and cooling garments. The only research found directly related to a disability was for MS and SCI, with most studies focusing on MS.

There is no significant research available on the efficacy of cooling garments, much of the research was outdated, and there was no indication in a rising research trend in this area, and the overall quality was rated "low".

The effectiveness of cooling garments is dependent on the type of health condition and the type of heat loss that the person requires (e.g. radiation, conduction, convection or evaporation of water).

Most of the SCI research sourced was directed to sports people/athletes during performance.

Cooling garments for MS

As mentioned above in the MS section, a literature review was published in 2010 examining the effectiveness of cooling techniques for thermally sensitive people with multiple sclerosis. The review found that:

- "Investigations have examined the use of cooling garments (microclimate cooling) to combat heat-induced worsening of symptoms in MS patients during daily activities or during exercise. Typically these garments come in two designs based on heat exchange properties.

- Active heat exchange garments are cooled by circulating liquid throughout the garment through a tubing network. Passive heat exchange garments have ice or gel packs that are inserted into the garment to provide the cooling effect.
- Cooling garments have demonstrated improvements in neurological function (motor performance and visual acuity) as well as perceived subjective benefits (feeling less fatigued) in thermally sensitive MS patients.
- A number of factors influence the ability of these garments to provide effective cooling: *1*) garment fit, *2*) location of cooling elements within the garment, *3*) cooling temperature and whether the cooling process is continuous or intermittent, *4*) body size and shape, and *5*) control and regulation of skin blood flow of the skin being cooled. Although microclimate cooling has been shown to be effective in reducing heat stress in MS, some caution must be considered because cooling garments may increase metabolic rate and arterial blood pressure, and decrease mechanical efficiency for patients with disabilities during the performance of physical work due to cooling equipment weight or restrictions in joint mobility. The cost of these garments also my limit accessibility and availability to some individuals with MS[87].

Air conditioning usage across Australia

Commented [AH8]: ABS data is old and not worth using/extrapolating. Find other air con usage data.

There has been no release of ABS data or comparable data since 2014 and no planned future release of data. In this paper we have referenced two data sources:

- The data from 2014 **(4602.0.55.001 - Environmental Issues: Energy Use and Conservation, Mar 2014)** is a sample report only (not a full census report), so there is no further subsets or micro data attached – meaning we cannot further break down the data to regions beyond capital city/balance of state.
- Previous releases of the data **(such as 4602.0.55.001 - Environmental Issues: Energy Use and Conservation, Mar 2011)** again were sample reports but only provided state figures (no capital city/balance of state data).

Air conditioning* - Number and percentage of homes: 2005-2017

- State only data.
- ABS data for all states from 2005 to 2014.
- Data provides the details of the number and percentage of homes with a form of air-conditioning.

Air conditioner used - Households ('000)	NSW	Vic	Qld	SA	WA	Tas	NT	ACT
2005	1,391.2	1,152.1	886.2	541.0	542.5	37.7	50.3	60.0
2008	1,579.0	1,428.3	1,043.4	550.2	661.9	71.5	56.6	80.0
2011	1,759.1	1,620.5	1,265.4	606.4	773.7	92.9	76.3	96.0

[87] Davis, loc cit.

2014	1,806.3	1,762.7	1,348.7	626.4	833.0	108.5	66.9	106.3
2017**	2,031.1	2,090.5	1,611.6	663.2	994.8	170.3	82.4	134.5
Air conditioner used (%)	NSW	Vic	Qld	SA	WA	Tas	NT	ACT
2005	53.7	60.1	57.8	84.1	68.8	19.2	91.9	47.9
2008	58.3	69.5	64.6	85.0	80.0	35.5	92.9	62.3
2011	64.2	75.5	73.3	91.3	86.3	44.4	93.9	69.5
2014	63.5	78.6	73.7	90.6	85.9	51.5	97.5	69.8
2017**	69.4	88.1	83.0	94.4	96.2	78.3	98.6	84.1

** refers to: reverse cycle/heat pump; evaporative; refrigerated (cools only); and other*

*** NOTE: Figures for 2017 estimate only; ABS has not released an update since 2014 and no expected future release. Figure is a statistical (exponential) calculation completed by NDIA only based on ABS data from 2005 to 2014.*

Conclusion:

There is evidence to support the DRHS requirement for AC or heating (or both) for these disability types:

- Multiple Sclerosis, Spinal cord injury, Tetraplegia (quadriplegia), Junctional Epidermolysis Bullosa, Stroke, ABI, Dravet syndrome, Parkinson's Disease, Complex Regional Pain Syndrome, Fibromyalgia, Familial disautonomia, Motor Neurone Disease.

In some circumstances there may be enough evidence to support the DRHS requirement for AC or heating (or both) for these disability types:

- ASD, Fanconi Anemia, Epilepsy, Lymphoedema (>Grade 1, Scleroderma, Cerebral Palsy, Systemic Lupus Erythematosus (SLE), Post-Polio syndrome/Poliomyelitis, Muscular Dystrophy.

There is not enough evidence to support the DRHS requirement for AC or heating (or both) for these disability types:

- Spina bifida.

Recommendations:

Commented [HA9]: REMOVE recommendations or policy advice. Retain content that speaks directly to evidence for effectiveness of heating/cooling systems.

- Given that some conditions have a temperature sensitivity to both heat and cold, a split system is likely to be the most cost effective system.
- The new DRHS policy, including the new DRHS operational guidelines does not effectively take into account atypical DRHS items, such as air conditioning.
    - For many of the health conditions considered above air conditioning meets the two criteria: directly related to the participant's ongoing functional impairment and required on an ongoing (regular) basis.
- The NDIA needs to develop a policy statement or additional guidance outlining the funding position for air conditioning and heating.
- For some participants it will be reasonable and necessary to fund DRHS to regulate environmental temperature to manage their thermoregulation dysfunction or temperature sensitivity, but this needs to be based on the severity of these symptoms.
- For some participants, environmental temperature regulation will not be an essential support and will be more about comfort. This differentiation is not reflected in the current policy.
- Basically, there will be some DRHS supports where the requirement is ongoing, directly related to a functional impairment, and will likely 'improve the participant's life through making them more comfortable', but this does not mean that the symptoms that they are intended to manage are significant or severe enough to warrant NDIS funding being used.
- Air conditioning and heating, particularly after the McKenzie ruling, are DHRS that poses a significant financial risk.

Appendix A

Table 1: Breakdown of summary of TAT advices

Commented [AH10]: REMOVE

Advices analysed	17	
Adult	16	
Child	1	
Declined – Yes	15	
Declined – No	2	
Advisor acknowledged known thermoregulation issue in the advice	6	Letter/report of recommendation by an OT or GP.
Theme - Vehicle Modifications	2	
Theme - Home Modifications	14	
Theme – Core (Consumables)	1	
Disability – MS	5	
Disability – Spinal Cord Injury	5	
Disability - Junctional Epidermolysis Bullosa	1	
Disability - Spina Bifida	1	
Disability – Stroke	1	

Disability - ASD	1	
Disability – ABI	2	
Disability - Fanconi Anemia	1	

Table 2: Summary of the advices

	HPRM#/ Participant age	Disability	Known thermoregulation link acknowledged in advice?	Theme	Recommendation	R&N
1	NED17/60796 Adult: 36 yo	MS	NO	Vehicle Modifications	Declined	Declined: does not meet Section 34(1)(c), (e) or (f). not necessary or value for money
2	NED17/76070 Adult: 48 yo	MS	NO	Home Modifications	Declined	Declined: No evidence has been supplied that air conditioning is the only method of thermoregulation available to the participant. The provision of air-conditioning is a day to day expense usually incurred by a family as detailed in Section 34.1 (e).
3	NED17/326318 Adult: 45 yo	Spinal Cord Injury	NO	Vehicle Modifications	Declined	Declined: Does not meet Section. 34.1(c), (d), (e) or (f). There is no evidence that alternate methods have been trialled by John to achieve optimal thermoregulation (such as cooling vests and other aids) which could be considered better value for money than air conditioning.
4	NED17/327114 Adult: 43 yo	Junctional Epidermolysis Bullosa	YES https://www.dermcoll.edu.au/atoz/junctional-epidermolysis-bullosa/ Accessed 03.03.2016.	Core - Consumables (Utility Bill payment)	Declined	Declined: Rules 2013 Part 5.1(d) which indicate that supports that relate to day to day living costs (such as utility fees) will not be funded. As described in the S.34 table above, cooling is an everyday cost. Payments and subsidies for additional power consumption are available from mainstream programs within NSW and from the Commonwealth. The NSW Government provides a Medical Energy Rebate for people on a fixed/low income and the NSW Department of Industry also offers other rebates on energy bills, including a Low income household rebate. The Department of Human Services provides an essential medical equipment

	HPRM#/ Participant age	Disability	Known thermoregulation link acknowledged in advice?	Theme	Recommendation	R&N
						payment for help with the additional cost of running medically required heating or cooling.
5	NED18/53088 Adult: 48 yo	Spina Bifida	NO	Home Modifications	Declined	Declined: **does not meet** Section 34.1(c), 34.1(f), or Rules 5.1b or 5.1d. There is insufficient evidence that air-conditioning of the participant's home is value for money relative to the benefits achieved and the cost of alternative supports. There is no evidence that it will improve the life-stage outcomes for the participant (rule 3.1b) or reduce the need for other types of NDIS funded supports now or in the future (rule 3.1f). In addition, air-conditioning or heating is the responsibility of any home owner/ tenant to provide for comfort during hot temperatures.
6	NED18/167470 Adult: 38 yo	MS	NO	Home Modifications	Declined	Declined: MET: Section 34.1a, 34.1d and Rules 5.1a, 5.1b, 5.1c, and 5.3. NOT MET: Sections 34.1c and 34.1f, 34.1(b)
7	NED18/227051 Adult: 51 yo	Stoke and unspecified psychosocial disorders	NO	Home Modifications	Declined	Declined: Without clinical justification and evidence that relates the request of air conditioning to the participant's disability and functional impairment, the request could be considered as day to day living costs
8	NED18/241211 24 yo	Autism with associated Intellectual Disability	NO	Home Modifications	Declined	Declined. Participant has a high degree of sensitivity to temperature extremes, with his self-harming and aggressive behaviours increasing when he is too hot or cold. The family current air-conditioning unit is old and unreliable. The supply and installation of an air-conditioning unit is considered a day-to-day living cost and the responsibility of the home owner to fund as per NDIS (Supports for Participants) Rules 5.1. (d)

	HPRM#/ Participant age	Disability	Known thermoregulation link acknowledged in advice?	Theme	Recommendation	R&N
9	NED19/10317 Adult: 57 yo	Spinal Cord Injury	YES OT report/letter acknowledged. OT Letter: Confirming that the participant experiences Autonomic Dysreflexia and body temperature regulation impairment stating that she requires air-conditioning.	Home Modification	Declined	Declined. OT letter acknowledged - However, the request does not meet the reasonable and necessary criteria for the NDIS to fund. Specifically, NDIS Supports for Participants Rule 5.1 (d) relates to a day-to day living cost.
10	NED19/11621 Adult: 52 yo	Spinal Cord Injury	YES OT Letter/Report. It is acknowledged that the participant experiences thermoregulatory dysfunction and that a range of alternative options for temperature regulation have been explored by the OT.	Home Modification	Declined	Declined: does not meet the reasonable and necessary criteria for the NDIS to fund. Specifically, NDIS Supports for Participants Rule 5.1 (d) relates to a day-to day living cost.
11	NED19/23838 Adult: 51 yo	ABI	YES The Occupational Therapist indicates that (OT) indicates that elevated body temperature results in poorer balance and mobility for Wayne, increasing his risk of falls.	Home Modification	Declined	Declined: The supply and installation of an air-conditioning unit is considered a day-to-day living cost It is acknowledged that the participant experiences thermoregulatory dysfunction as a result of the functional impairment of his disability and there has been some consideration of alternative options for temperature regulation explored by the OT
12	NED19/70209 Adult: 52	ABI	YES As part of her MS symptoms, Karen experiences severe temperature sensitivity for both warm and cool weather. Letters from her Occupational Therapist and General	Home Modifications	Declined	Declined. The OT has not reported to have considered any alternative cooling strategies which may support the participant to achieve the same outcome at a substantially reduced cost. The supply and installation of an air-conditioning/heating unit is considered a day-to-day living cost and the responsibility of the home owner or tenant to fund as per NDIS (Supports for Participants) Rules 5.1.(d).

	HPRM#/ Participant age	Disability	Known thermoregulation link acknowledged in advice?	Theme	Recommendation	R&N
			Practitioner recommend that Karen would benefit from a split system air conditioner/heater in her home.			
13	NED19/141779 Adult: 63 yo	MS	NO	Home Modification	Declined	Declined. The OT has not demonstrated, through the participant's lived experience or trial if this support is likely to assist her in managing her MS symptoms to the extent that it will increase her independence with daily activities and reduce her need for other types of support (Supports for Participants Rule 3.1 (f)).
14	NED19/175962 Adult: 46 yo	MS	NO	Home Modifications	Declined	Declined. The OT has not demonstrated, through the participant's lived experience or trial if this support is likely to assist her in managing her MS symptoms to the extent that it will increase her independence with daily activities and reduce her need for other types of support (Supports for Participants Rule 3.1 (f)). The OT has not sufficiently considered alternative supports (portable air-conditioner, lower cost air-conditioner, air conditioning in only one frequently used living area) which could support her to achieve sufficient cooling to improve her independence. (Supports for Participants Rule 3.1 (a)).
15	NED19/185598 Adult: 29 yo	Spinal Cord Injury	YES "The participant is at risk of Autonomic Dysreflexia, and is reported to have experienced this in the past as a result of overheating. "	Home Modifications	NOT DECLINED Decision appears to be related to thermoregulation issue and participant at risk of Autonomic Dysreflexia.	NOT DECLINED. Air-conditioning would allow the participant to access the main living area in his home throughout all seasons. Because of the tropical climate that he lives in, the participant is currently unable to access key areas of his home for daily activities and spending time with family and friends for a large proportion of the year. There is evidence that this support will substantially improve his life stage outcomes (Supports for Participants Rule 3.1 (b)). Several alternative options were considered and found not to meet the participant's needs (Supports for Participants Rule 3.1 (a)). A cooling vest would require support from an attendant and may place him at risk of skin injuries. Ceiling fans currently provide insufficient cooling and a portable air-conditioner is not appropriate for the large size of the room.

	HPRM#/ Participant age	Disability	Known thermoregulation link acknowledged in advice?	Theme	Recommendation	R&N
16	NED19/185733 Adult: 57	Spinal Cord Injury	YES At risk of autonomic dysreflexia "In warmer weather, her inability to regulate body temperature can result in excessive sweating which will have significant impact on her skin integrity, placing her at a high risk for serious pressure injuries" Advisor research: Michelle B. Trbovich, John P. Handrakis, Nina S. Kumar & Mike J. Price (2019) Impact of passive heat stress on persons with spinal cord injury: Implications for Olympic spectators, Temperature, DOI: 10.1080/23328940.2019.1631730 - People with SCI demonstrate altered thermoregulatory physiological response to passive heat stress. - "Feeling too hot or cold at home" has been identified as a barrier that affects health related quality of life for people with SCI. - Passive heat stress and exposure to cool temperatures impacts cognitive performance of people with SCI.	Home Modifications	NOT DECLINED Decision appears to be related to thermoregulation issue and participant at risk of Autonomic Dysreflexia	NOT DECLINED. Air-conditioning will allow the participant to access the essential areas of her home used for daily activities at a safe temperature. There is evidence that this support will substantially improve her life stage outcomes (Supports for Participants Rule 3.1 (b)). Alternatives to air-conditioning were considered and found not to meet the participant's needs (Supports for Participants Rule 3.1 (a)). Prior to approval of any funds related to an air-conditioning system it should be communicated to the participant that future electricity costs for operating this system are not the responsibility of the NDIS to fund as outlined below.
17	NED19/196196 1 Child: 8 yo	Fanconi Anemia	NO	Home Modification	Declined	Declined. The requested split system air-conditioner for the participant's bedroom does not meet Section 34.1c or Rule 5.1d

Appendix B – Literature Review - Cooling Garments

Each research item has been given a quality of evidence rating using GRADE and CRAAP Guidelines as per the ***Draft TAT Research Team: Work Processes & Research Tools, 2019***.

Research Focus	Document Details	Research Type / Summary	Quality of Evidence
MS	Y. Ku et al., "Physiologic and Functional Responses of MS Patients to Body Cooling", American Journal of Physical Medicine & Rehabilitation, vol. 79 - no. 5, 2000, pp 427-434. https://journals.lww.com/ajpmr/Abstract/2000/09000/Physiologic_and_Functional_Responses_of_MS.4.aspx	Cohort study with the objective to compare the responses of multiple sclerosis (MS) patients to short-term cooling therapy using three different vest configurations. Conclusions: Results show that the various garment configurations tested do not produce similar thermal responses in all MS patients.	MODERATE Abstract / A study related to vest configurations
MS	A. Gossmann et al., "No Effect of Cooling on Cognitive Fatigue, Vigilance and Autonomic Functioning in Multiple Sclerosis", J Mult Scler, vol 1, no 2, 2014. https://www.researchgate.net/profile/Helmut_Hildebrandt/publication/271505191_No_Effect_of_Cooling_on_Cognitive_Fatigue_Vigilance_and_Autonomic_Functioning_in_Multiple_Sclerosis/links/54c92a570cf2f0b56c21e34b.pdf	Randomized placebo controlled study to determine the effects of cooling on cognitive fatigue and autonomic functioning with MS patients using cooling vest. Conclusion: Cooling has no impact on experienced cognitive fatigue and on cognitive performance in MS patients.	HIGH Research is the most current and relevant available.
	Y. Ku et al., "Physiologic and Functional Responses of MS Patients to Body Cooling Using Commercially Available Cooling Garments", 1999. https://ntrs.nasa.gov/search.jsp?R=20000112923	Controlled study with the objective to document and compare the patient response to two passive cooling vests and one active cooling garment (The Life Enhancement Technology, Inc. (LET) lightweight active cooling vest with cap, the MicroClimate Systems - MCS) with regard to physiologic and functional responses. Conclusions: These results show that the garment configurations tested do not elicit a similar thermal response in all MS patients. Cooling with the LET active garment configuration resulted in the lowest body temperatures for the MS subjects; cooling with the MCS vest was least effective. For functional responses, the LET test group performed better than the other two vests.	LOW Research is outdated / No publication information could be found / Bias and conflict of interest may be an issue / A study related to vest types/brands

Research Focus	Document Details	Research Type / Summary	Quality of Evidence
MS	Y. Nilsagard et al., "Evaluation of a single session with cooling garment for persons with multiple sclerosis – a randomized trial", Disability and Rehabilitation: Assistive Technology, Vol 1, no 4, 2006, pp. 225-233. https://www.researchgate.net/publication/241762688_Evaluation_of_a_single_session_with_cooling_garment_for_persons_with_multiple_sclerosis_-_a_randomized_trial	Randomized trial which investigates the objective and subjective effects of wearing the Rehband cooling garment using 43 heat-sensitive persons with multiple sclerosis (MS), comparing active treatment with placebo. Conclusions: Active cooling with a Rehband: vest is likely to have a positive effect on everyday life in heat-sensitive persons with MS.	LOW Bias and conflict of interest may be an issue / Brand related research / No evidence of journal publication
MS	A. Meyer-Heim et al., "Advanced lightweight cooling-garment technology: functional improvements in thermo-sensitive patients with multiple sclerosis", Multiple Sclerosis, vol 13, no 2, pp. 232-237, 2007. https://journals.sagepub.com/doi/abs/10.1177/1352458506070648	A crossover study investigating the effectiveness of an advanced lightweight cooling-garment technology based on aquatic evaporation, a single-blinded balanced crossover study was performed on 20 patients with an Expanded Disability Status Scale score ≤6.5. Conclusions: The results using a tight-cuff cooling-garment prototype for peripheral cooling suggest improvement of a timed-walking test, leg-strength, fine-motor skills and subjective benefits. Preliminary data of the heart rate variability (HRV) including six patients suggest that the MS patients show an abnormal HRV after sham condition, which is normalized after cooling. Authors found the results to be encouraging in promoting further adaptations of the prototype to increase its cooling properties and ameliorate the practicability of the cooling garment.	LOW Research is dated / low number of subjects / research is working with prototype
MS	M. Geisler et al., "Cooling and Multiple Sclerosis: Cognitive and Sensory Effects", Journal of Neurologic Rehabilitation, vol 10, no 1, pp. 17-22, 1996. https://journals.sagepub.com/doi/abs/10.1177/154596839601000103	Control study on effects of cooling on sensory and cognitive processes were investigated in heat-sensitive multiple sclerosis (MS) patients and healthy control (HC) subjects. The Life- Support cooling jacket was used to lower core body temperature by one degree or more. Auditory event-related potentials and neuropsychological test performance were examined in both the cooled and the normal states. Eight MS patients and eight HC sub jects underwent two hours of cooling on one day and two hours of sham cooling on another day (order counterbalanced across subjects). Conclusions: The MS patients had significantly poorer neuropsychological performance than HC subjects but performance on most of these tests was	LOW Research is dated / Bias and conflict of interest may be an issue / Brand related research

Research Focus	Document Details	Research Type / Summary	Quality of Evidence
		not affected by cooling. Since the electrophysiological and neuropsychological measures tapped a broad range of CNS functions and brain areas, the data suggest that the marked clinical improvement seen with cooling in heat-sensitive MS patients is not accounted for by facilitation of the sensory and cognitive processes of the CNS.	
MS	L. Robinson, "Body cooling may not improve somatosensory pathway function in multiple sclerosis", American Journal of Physical Medicine & Rehabilitation, vol 76, no 3, pp 191-196, 1996. https://journals.lww.com/ajpmr/Abstract/1997/05000/BODY_COOLING_MAY_NOT_IMPROVE_SOMATOSENSORY_PATHWAY.5.aspx	Using 20 subjects the study tested the hypothesis that reducing core body temperature in subjects with multiple sclerosis (MS) improves the cortical somatosensory evoked potential (SEP) response. Conclusions: Although some reports suggest symptomatic improvement during cooling in subjects with MS, this improvement may not be associated with changes in the SEP.	LOW Research is dated / Small sample size
SCI	K. Griggs et al., "Cooling Athletes with a Spinal Cord Injury", Sports Medicine, vol 45, no 1, pp9-21, 2015. https://link.springer.com/article/10.1007/s40279-014-0241-3	Literature review to examine scientific literature that addresses the application of cooling garments in individuals with an SCI. Conclusions: From the studies reviewed, wearing an ice vest during intermittent sprint exercise has been shown to decrease thermal strain and improve performance. These garments have also been shown to be effective during exercise in the able-bodied. Future studies are needed to ensure that research outcomes can be translated into meaningful performance enhancements by investigating cooling strategies under the constraints of actual competition. Cooling strategies that meet the demands of intermittent wheelchair sports need to be identified, with particular attention to the logistics of the sport.	LOW Aspects are relevant

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Version Control

Version No.	Date	Drafting Officer/Author	Approved/Received	Description of change	Date of review
V0.1	25/10/19	Craig 47F - pe & Annika 47F - perso			
V0.2	08/04/20	Craig 47F - pe	Karyn 47F - person	Reference to related TAB research ("RES HWB/AT Thermoregulation Dysfunction and Seizures") added	

Research Request – Central Sensitivity Syndromes and Functional Neurological Disorder

Brief	Information to assist Assessors from NAWM with their decisions for access requests relating to these specific conditions.
Date	Due 24 December 2019
Requester	Katrin s47F - personal p – Assistant Director TAT
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Cleared by	

Contents

Please note:

The research and literature reviews collated by our TAT Research Team are not to be shared external to the Branch. These are for internal TAT use only and are intended to assist our advisors with their reasonable and necessary decision making.

Delegates have access to a wide variety of comprehensive guidance material. If Delegates require further information on access or planning matters they are to call the TAPS line for advice.

There are already a significant number of resources, including commissioned expert reports and external specialist publications and clinical guidelines, which are available to NDIA staff to use in delegate decision making.

This paper aims to bring these resources together as a starting point and provide any additional information as required.

Scope of this document

The National Access and Workload Management Branch (NAWM) have requested assistance from TAT with assessing access for prospective participants with Chronic Regional Pain Syndrome, Functional Neurological Disorder aka Conversion Disorder, Chronic Fatigue Syndrome & Fibromyalgia.

- *Note: While the Disability Related Health Supports (DRHS) policy has not changed any of the established NDIS access criteria or legislation, the fact that 1) Participants can now receive DRHS through the NDIS and 2) A planner must now plan for the 'whole of person', means that the 'most appropriate funder/provider' proviso (under s34.1.f) no longer eliminates the typical types of supports that the NDIS could potentially fund for this cohort.*
- *This is causing an increase in access requests being made for these health conditions, based on their diagnosis and lived/reported significant functional impairment(s)*

The symptoms and experiences of people with these health conditions are individual and often complex, consequently it is often challenging for medical experts to determine a diagnoses.

Even once a diagnosis has been made, it remains difficult for NDIS access assessors to apply the Access - disability requirements criteria, particularly to determine permanency and the need for NDIS supports for life, compared to mainstream health treatment and supports.

Also, as the pathophysiology *[the disordered physiological processes associated with disease or injury]* of these conditions are still poorly understood, it is challenging for access assessors to determine whether these cohorts have exhausted all evidence-based, clinical, medical or other treatments.

- None of these conditions are included on the List A, B, C or D for common conditions that meet NDIS Access – disability requirements.
- While the outcomes of AAT hearings are not intended to set a precedent, the NDIA legal team's application of the access legislation against these health conditions in AAT cases is the only direction the NAWM have to guide their decision making.

Previous AAT Cases

The majority of these AAT cases were relating to access and were deemed 'access not met'. Generally, it was only in severe cases that access was met, where permanency and functional impairment were established through expert reports.

See APPENDIX A for full summary of AAT cases relating to these conditions to date.

Previous TAT advices

There are several previous TAT access advices relating to these health conditions. Most of these advices are from 2017 & 2018.

These TAT advices highlight that CRPS, CFS, FND, fibromyalgia, along with, Postural tachycardia syndrome (PoTS), depression, anxiety and other psychosocial disability, Lyme's disease & lupus often present as complex comorbidities.

See APPENDIX B for full summary of TAT advices relating to these conditions.

Central sensitivity syndromes / Central regional pain syndromes – Common co-morbidities

Physicians often experience difficulty diagnosing patients who present with reported chronic pain and multiple other non-specific symptoms. This is because reported and observed symptoms may result in multiple diagnoses.

The nomenclature of 'central regional pain syndrome' or 'central sensitivity syndrome', or their variations, are increasingly used to collectively refer to all chronic pain disorders with a common pathophysiology.

An advocacy website called **Central Sensitivity Syndrome Survivor's Guide** comprehensively summarises this

> "Central Sensitivity Syndrome or Central Sensitization Syndrome (CSS) is a comorbid syndrome marked by "central sensitization" in which holds overlapping features that can cause significant disability. Such over lapping conditions are Fibromyalgia, Myofascial Pain, and Chronic Fatigue Syndrome. The biophysiologic mechanisms of these conditions are multifactorial; neuroendocrine abnormalities with central sensitization, however, seem most important. Though psychological distress is present in these patients, keep in mind this is not a psychiatric illness. Management is mostly supportive and includes patient education, psychological support, behavioral modification, physical exercise, and various serotonergic and noradrenergic medications. Like Chronic Fatigue Syndrome and Fibromyalgia, there is a higher preponderance of females with this condition than men. Accumulated recent data support the hypothesis that all these disorders share a common biophysiologic mechanism of neurohormonal dysregulation caused by perhaps neuroendocrine or adrenaline. It seems the most important neurologic aberrations comprise central sensitization, which involve molecular, chemical, and functional changes in the central nervous system, resulting in an amplification and spread of pain, and intensification of other sensations".
>
> "The concept that several of these related conditions should be grouped under the unified heading of "Central Sensitivity Syndrome" was first presented by Dr. Muhammad Yunus, rheumatologist, professor of Medicine at the University of Illinois College of Medicine at Peoria, and pioneer in fibromyalgia research. Dr. Yunus discovered that many of these conditions (e.g., fibromyalgia, myofascial pain syndrome, irritable bowel syndrome, chronic fatigue syndrome, headaches and restless legs syndrome) shared several characteristics, including pain, poor sleep, fatigue, extreme sensitivity to stimuli, and an absence of abnormal tissue structure. The connecting thread for these conditions appears to be central sensitization, which simply means that the central nervous system has an exaggerated response to stimuli"[1].

Dr Muhammad B. Yunas's critical literature review from 2007 titled '*Fibromyalgia and Overlapping Disorders: The Unifying Concept of Central Sensitivity Syndromes*' can be found here.

In 2007 Yunas concluded that the concept of CSS seems viable and it "based on mutual associations among the CSS conditions as well as the evidence for central sensitizations among several CSS members… [and that] CSS is an important new concept that embraces the biopsychosocial model of disease. Further critical studies are warranted to fully test this concept. However, it seems to have important significance for new directions for research and patient are involving physician and patient education. Each patent, irrespective of diagnosis, should be treated as an individual

[1] CSS Survivor's Guide, "Central Sensitivity Syndrome (CSS) - Central Sensitization", [website], 2019, http://css.dewarlorx.com, (accessed 18 December 2019)

considering both the biological and psychosocial contributions to his or her symptoms and suffering[2].

The proposed members of the CSS family include: Fibromyalgia, Chronic Fatigue Syndrome, Irritable Bowel Syndrome (IBS), Tension type headache (T-T Headache), Migraine, Temperomanibular disorders (TMD), Myofascial pain syndrome (MPS), regional soft-tissue pain syndrome (RSTPS), periodic limb movements in sleep (PLMS) multiple chemical sensitivity (MCS), Female urethrl syndrome (FUS), Interstitial cystitis (IC), Post traumatic stress disorder (PTSD)[3].

This publication has comprehensive information on the mutual associations amongst these CSS conditions.

A research publication from 2011 highlights how fibromyalgia is commonly linked with other regional pain syndromes such as tempromandibular disorder (TMD), irritable bowel syndrome (IBS), interstitial cystitis (IC), headache, chronic low back pain, and chronic neck pain.

This publication states that:

> "A persuasive body of evidence now demonstrates that sensitization represents a unifying pathophysiological mechanism among these painful disorders. It has been proposed that these syndromes have more in common than previously thought, specifically that they are characterized by a dysregulation of peripheral afferents and central nervous system pathways. Given the shared pathophysiological mechanisms, these disorders have been coined "central sensitivity syndromes" (CSS)"[4].

Another publication from 2015 discussed how central sensitization are a collective group of disorders stating that: "There is considerable overlap among syndromes such as fibromyalgia, chronic fatigue, irritable bowel syndrome, chronic pelvic pain, and chronic daily headache"[5].

Diagnoses, Self-diagnoses, and Symptoms that May Suggest Central Sensitization Syndrome (Especially If Copious)[6]	
Abdominal bloating	Immune deficiency (self-diagnosed)
Abdominal pain, chronic abdominal pain	Interstitial cystitis, painful bladder syndrome
Adrenal insufficiency (self-diagnosed), adrenal fatigue	Irritable bowel syndrome
Alopecia, hair loss, trichotillomania	Joint pains
Anxiety	Low testosterone or hypogonadism (with normal test results)
Atypical facial pain	Lupus (self-diagnosed)
Atypical or non-cardiac chest pain	

[2] Yunus, MB, 'Fibromyalgia and Overlapping Disorders: The Unifying Concept of Central Sensitivity Syndromes', The University of Illinois College, 2007, https://www.ourcpc.com/wp-content/uploads/2016/03/Yunus-central-sensitivity-2007.pdf, accessed 9 December 2019, p.339.

[3] Ibid, p. 341.

[4] L. Kindler et al., "Central Sensitivity Syndromes: Mounting Pathophysiologic Evidence to Link Fibromyalgia with other Common Chronic Pain Disorders", Pain Manag Nurs., Vol 12, No 1, pp. 15-24, 2012, https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3052797/

[5] ibid

[6] ibid

Autoimmune disorder (self-diagnosed)	Lyme disease, chronic Lyme disease (self-diagnosed)
Autonomic disorder (self-diagnosed)	Meniere disease
Black mold, toxic black mold (self-diagnosed)	Morgellons disease (self-diagnosed)
Brain fog, fibrofog	Multiple chemical sensitivities
Burning mouth syndrome	Multiple drug allergies or intolerances (self-diagnosed)
Burning tongue	Multiple food allergies or intolerances (self-diagnosed)
Candida or chronic yeast infection	Myofascial pain syndrome
Chiari malformation	Palpitations
Chronic low-back pain	Panic disorder, episodes, attacks
Chronic non-specific light-headedness	Pelvic pain, chronic pelvic pain, premenstrual syndrome
Chronic pain	Polycystic ovary syndrome
Chronic pelvic pain	Porphyria (self-diagnosed)
Chronic prostatitis	Post-deployment syndrome
Chronic tension or migraine headaches	Post-traumatic stress disorder
Chronic testicular or scrotal pain	Postural orthostatic tachycardia syndrome (POTS)
Chronic whiplash-associated disorders	Pseudotumor cerebri
Chronic widespread pain	Schamberg disease, soft tissue tumors
Complex regional pain syndrome	Sick building syndrome
Delusions of parasitosis	Sjögren syndrome (blamed for multiple symptoms)
Depression or bipolar disorder	Temporomandibular disorders, temporomandibular joint pain
Dizziness	Thyroid disease (with normal test results, usually self-diagnosed)
Edema or swelling complaints not evident on examination	Tinnitus
Ehlers–Danlos syndrome	Vulvodynia, vulvar vestibulitis
Fatigue or chronic fatigue	
Fibromyalgia, myalgic encephalitis	
Hormone imbalance	
Hyperventilation	
Hypoglycemia (self-diagnosed)	

While Functional Neurological Disorder (FND) is not considered under the Central Sensitivity Syndrome (CSS) umbrella of conditions, chronic pain is a common symptom of patients with FND and overlaps with these CSS conditions due to the neurological dysfunction factor.

The U.S. National Organization for Rare Disorders states that:

> "Anxiety and depression can sometimes cause physical symptoms which overlap with FND symptoms. For example, panic attacks can present with symptoms such as pins and needles

in the fingers or mouth and depression often causes poor concentration or fatigue. Anxiety and depression are common in patients with FND but many patients do not have such problems.

Chronic pain is also common in patients with FND including fibromyalgia, which is also related to disturbed nervous system functioning. Pain disorders are also usually associated with fatigue, sleep disturbance, and poor concentration. Migraine and chronic headaches are also common.

Other functional disorders including irritable bowel syndrome, or overactive bladder syndrome are more common in patients with FND"[7].

Similarly to FND, Chronic Fatigue Syndrome (CFS) does not fit neatly under the Central Sensitivity Syndrome umbrella, but is closely associated with many of the conditions and symptoms common in CSS patients and one aspect of the pathophysiology of CFS is an altered central nervous system conditioning[8].

In 2002, the Royal Australasian College of Physicians (RACGP) published CFS Clinical Guidelines which state that:

- "Fatigue is a central feature of many clinical syndromes, including CFS, fibromyalgia, irritable bowel syndrome, major depression, anxiety and somatoform disorders. These syndromes also share other, non-specific symptoms, including musculoskeletal pain, sleep disturbance, neurocognitive impairment and mood changes. Fibromyalgia, in particular, is a closely related syndrome, differing mainly in its relative emphasis on musculoskeletal pain rather than fatigue"[9].

[7] NORD, "Functional Neurological Disorder", [website], 2019, https://rarediseases.org/rare-diseases/fnd, (accessed 18 December 2019)

[8] The Royal Australian College of Physicians, "Chronic fatigue syndrome: Clinical practice guidelines — 2002", MJA, Vol 176, p. 32, 2002, https://www.mja.com.au/system/files/issues/cfs2_2.pdf

[9] ibid, p.28.