

Themis



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Inaugural Periodical of ME/CFS Legal Resources

In this issue:

- Introduction to *Themis*
- Issues that impact ME/CFS
- Navigating Case Law Resources
- Long-Covid



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1. WELCOME

1.1. What is ME/CFS Legal Resources?

ME/CFS Legal Resources was first conceived in 2000. Born out of the experience of four years of Myalgic Encephalomyelitis /Chronic Fatigue Syndrome ('ME/CFS') related legal issues (eg Discrimination, Insurance, Workers Compensation, Disability Support



Pension, etc), it was clear that there was a significant void existed within the ME/CFS

community with respect to advocates and an absence of knowledge of the condition within the legal fraternity.

The isolation of ME/CFS for many with the condition, coupled with the rise of the internet, made the concept of online accessible resources the most logical option.

In January 2001, the first ME/CFS Legal Resources website was launched. As the years progressed and hosts folded, the site was moved to new locations at various times.

In 2014, the ME/CFS Legal Resources Facebook page was created, providing a more effective and timely upload of relevant information and some interactions to be facilitated.

In 2017 the site was hacked and ultimately 'squatted' by persons unknown. Whilst ultimately a new site was relaunched, the time commitment to content proved too much and is still very much a work in process.

ME/CFS Legal Resources has made a number of submissions to various government inquiries where the issues impacting people with ME/CFS were relevant.



ME/CFS Legal Resources will continue to contribute to, and evolve with, the challenges and needs of the condition, now and into the future.

1.2. Why Themis?

Themis is the goddess and personification of justice, divine order, law, and custom. Themis is one of the twelve Titan children of Gaia and Uranus, and the second wife of Zeus. Themis is associated with oracles and



ME/CFS Legal Resources

Informing those with ME/CFS since 2001
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prophecies, including the Oracle of Delphi.

Her symbol is the familiar Scales of Justice that we associate with the law and justice.

This periodical is focused upon helping people to achieve justice – to take control of their situation and stand up for their rights.

Themis is very much about empowering people with ME/CFS – helping them to learn where to find information to assist with the issues that they face on a daily basis, and potentially become aware of issues that may be impacting them without necessarily being aware of them.

1.3. Format

The format of this periodical will adjust and evolve to the needs of those who utilise it and the topics that arise between each issue.

Case law is an important source of direction and will feature prominently – particularly in the areas of the NDS and Centrelink where the Administrative Appeals Tribunal hears the majority of disputes that can help people with ME/CFS to plan their approach to claims.

On occasion there are journal articles or opinion articles that appear that provide insight into legal issues of relevance.



From time to time there are inquiries in which the ME/CFS community has an interest where people will be encouraged to contribute, or reports where their outcome is of relevance to ME/CFS.

1.4. Frequency of Release

Producing a periodical of this nature is an onerous task. The intention is to release each issue on a quarterly basis. Case law is an evolving creature, however cases of significance are not often published within a 3 month period.

The objective is consistency of information in a timely manner so that it can be used by those who need it.



1.5. Areas of Relevance

As anyone with ME/CFS knows from the lived experience of the condition, the issues that arise, directly or indirectly, are almost endless. Some of the more common issues are:

- Accessing and navigating the national disability insurance scheme ('**NDIS**');
- Accessing disability services;
- Accessing and retaining the DSP;
- Accessing Insurances such as Income Protection, Total, Permanent Disability, Workers Compensation, Credit Insurance, etc;
- Accessing superannuation;
- Access to housing;
- Managing employment and cessation of employment;
- Managing discrimination issues;
- Managing with financial difficulties;
- Managing child welfare and protection;
- Managing family law issues;
- Managing domestic violence issues;
- Managing testamentary issues;
- Interacting with the medical, hospital and allied health system;
- Acquiring of medical and other evidence;

- Navigating the legal system (ie accessing lawyers, legal centres, appearing unrepresented, filing actions, etc);



At the more obscure end of the spectrum are:

- Recording of conversations;
- Interacting with Independent Medical Examiners;
- Implementing disability plans;
- Accessing travel insurance;
- Australian Taxation Office issues;
- Managing police and incarceration issues;
- Medical misdiagnosis;
- Medical negligence

There are many dozens of other issues that arise as a result of, or



a corollary to, ME/CFS – aside from the usual legal issues that people face in their normal course of their lives.

1.6. Contributions

Themis is focused on informing people. The ME/CFS community is a diverse melting pot of people with various experiences, qualifications and employment disciplines. Contributions of relevance, experiences, ideas, insights and opinions are welcome at any time.

Some topic suggestions might include:

- Applying for the NDIS;
- Applying for the DSP;
- Altering an NDIS plan;
- Appearing before the Administrative Appeals Tribunal ('AAT');
- Obtaining Legal Aid funding;
- Claiming on TPD insurance;
- Compelling a landlord to provide a safe housing environment;

Feel free to email mecfslegal@yahoo.com.au with your contributions or questions.

MOVE CONSISTENTLY AND CHANGE THINGS

Mark Zuckerberg's Facebook motto of 'move fast and break things' might appeal to some, but history might suggest such an approach is both problematic and ultimately damaging. People with ME/CFS have inconsistent capacity and limited supports to effect the change that is required to improve the circumstances in which they exist. The past 40 years of history have demonstrated that change has been gradual, but progressive. In the area of law change has been slow and evolutionary. By bringing together the elements that make up that progress, people with ME/CFS can apply that knowledge to progress change. We can't move fast. But we can work smarter and consistently to effect change.



2. LEGAL ISSUES AND ME/CFS

2.1. Why Legal Issues?

ME/CFS, whether we like it or not, is a contested condition.

Some might suggest that this is by design, because of the expense the condition represents to various elements in society, be they government (eg Centrelink, Medicare, NDIS), non-government enterprises (eg workers compensation, superannuation, insurers) or individuals (eg property settlement, estate entitlement).

ME/CFS is also poorly understood, within the medical profession, the legal profession and society as a whole.

People with ME/CFS are often vulnerable and therefore a target for violence, abuse, neglect and exploitation ('VANE').

It is for these reasons that legal issues arise – be they overt or discrete.

2.2. Impact on Health

The health and well-being of people with ME/CFS are impacted by the social determinants of health (**Figure 1**).

SOCIAL DETERMINANTS OF HEALTH

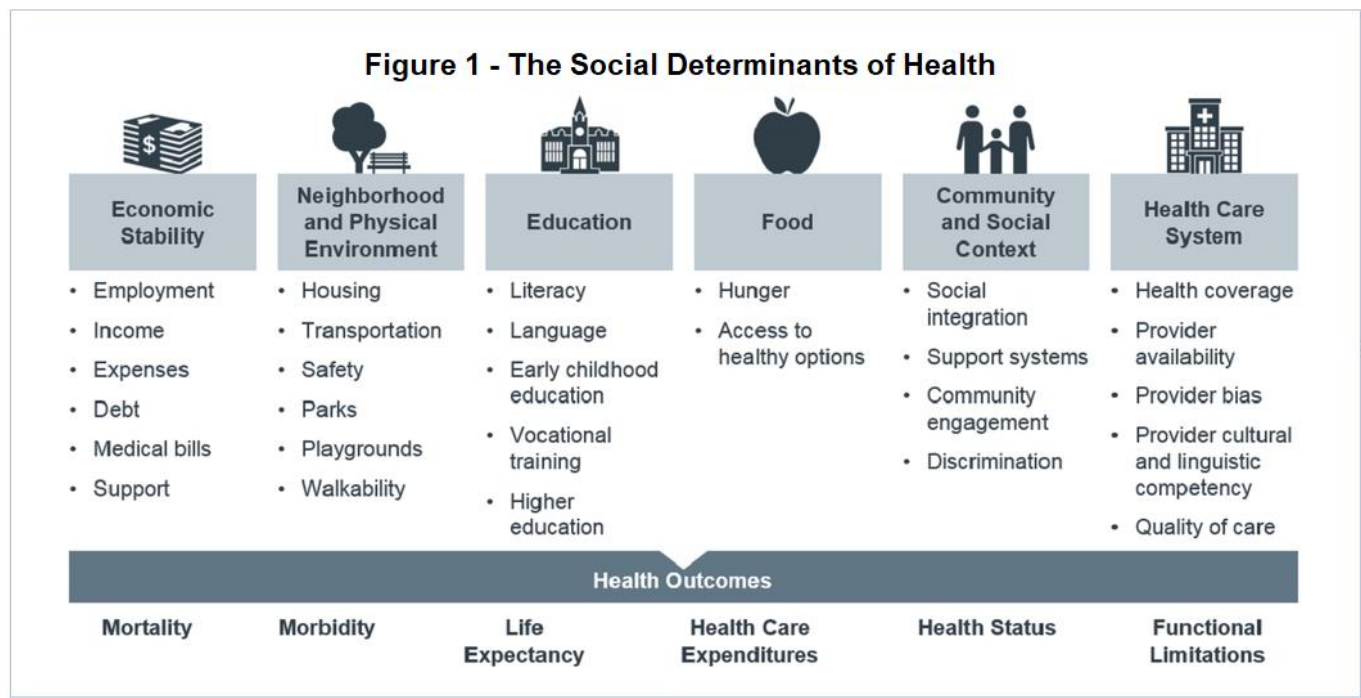
- Social determinants are the environmental conditions (or place) in which people are located;
- Conditions include elements such as the social, economic, and physical factors;
- The place in which people live are impacted by material attributes, patterns of social engagement and the sense of security and well-being a person experiences;
- Resources that enhance quality of life also impact health

LEGAL DETERMINANTS OF HEALTH

- The law impacts health in multiple ways, by structuring, perpetuating, and mediating the social determinants of health;
- The law has the ability to protect health, promote well-being, and reduce health inequalities;
- The law can be a powerful means for advancing health giving effect to:
 - Sustainable Development Goals in particular, the provision of Universal Health Coverage (UHC);
 - governance of national and global health institutions;
 - implementation of evidence based health interve
 - building legal capacity.



Figure 1 - The Social Determinants of Health



The social determinants of health are those core components that make up the day-to-day life of all people in society (ie economic stability, physical environment, education, food, health care, community and social contact).

For most who have lived the experience of ME/CFS, these are the areas that are most significantly impacted by the condition.

When elements of these determinants are impacted (eg reduced income, homelessness, lack of access to healthcare, inappropriate treatments) our health is potentially impacted.

In ME/CFS this may well equate to harms, exposure to VANE or an increase in the severity of the condition. In extreme cases, it can result in death or a reduction in life expectancy.

The law too is a determinant of health. The law has the ability to impact these social determinants by changing the circumstances in which people with ME/CFS can exist.



Whether it be:

- the assistance a person with ME/CFS needs to access a income (eg via the disability support person ('**DSP**'), workers compensation or an income protection);
- the financial security that accompanies a lump sum (eg negligence payment, total and permanent disability payment, access to the proceeds of a property settlement or an entitlement to a deceased estate);
- the ability to fend off medical abuse (eg attempt to take children, forced medical care, forced treatment), access to safe and secure (eg accessing public housing, having an unsafe residence cleaned or avoiding eviction);
- the ability a person with ME/CFS to access disability services (eg access to the NDIS; access to council disability services);
- anyone of the many other issues that might arise in which intervention is needed;

the law can assist to change the circumstances of the individual such that their health outcomes improve because the social determinant is changed.

2.3. Access to Justice

Justice is a nefarious construct – it means different things to different people. It is a moral concept, based on ethics, rationality, law (both natural and man-made) and religious doctrine, equity, fairness and rights.

For most, justice is a concept of fairness – a proper and reasonable outcome to an issue in dispute. The ability to access justice in ME/CFS is problematic. Access can be impeded for many reasons:

- Availability of knowledgeable, willing and/or capable advocates;
- Scarcity of physical and financial resources;
- Knowledge and/or awareness of rights and the method of protecting them;
- Functional capacity;
- Financial capacity;



-
- Ability to collate and/or secure the evidence;
 - Limitations within the medical fraternity;
 - Language and cultural barriers;
 - Other issues and limitations;

Achieving justice is difficult – not impossible. Those who have the function, means and ability can pave the way for others by stepping forward and taking action.

In the 24 years in which ME/CFS Legal Resources has existed, there have been many Australian and overseas decisions, policies and legislations that have changed to the benefit of ME/CFS. This came because of advocates, legal cases and activism.

2.4. Bridging the Gap

ME/CFS Legal Resources cannot resolve the access to justice issues. Achieving such a task is well beyond the scope of the project. ME/CFS legal can, however, assist in bridging the gap by providing:

- Exposure of the key issues;
- Education where possible;
- Resources that are focused and relevant;
- Advocating where required;

The institutional biases and barriers that exist with respect to ME/CFS are ingrained within society.

Change is incremental. ME/CFS Legal Resources aims to empower those are capable, to change their own situation for the better and improve the opportunities for others.



3. SEARCHING LEGAL ISSUES

3.1. 'Teach a Man to Fish'



There is an old proverb - "Give a man a fish, and you feed him for a day; teach a man to fish and you feed him for a lifetime".

Legal research is an acquired skill. It takes refining and repetition to learn over time. It takes knowledge of the law, legislation and terminology.

Expecting a lay person with ME/CFS to acquire all those skills within a short period of time (or even longer) is not achievable.

Providing access to various sources that can be of assistance, with basic instructions of how to search these locations may make some previously unknown or inaccessible resources – more accessible.

3.2. Search Methodology

Conducting searches is an acquired skill that can become quite complex in terms of the way search terms are constructed. At its most basic, however, it merely requires submitting the search terms (ie the words) that you want to use – eg chronic fatigue syndrome..

If you wish to use an exact phrase and improve accuracy and relevance, use quotation marks – eg "chronic fatigue syndrome".

If you wish to include other terms, you can use Boolean operators to connect you terms together. Some of the common operators are **AND**, **OR** and **NOT** – eg "chronic fatigue syndrome" and legal. You can add multiple operators within the search terms to keep refining your results

This basic approach to searching can be applied to most search engines.



3.3. Google

Google (www.google.com.au) is a very useful tool but it is not necessarily an effective legal research tool. It can, however, be used as a way to access some information on legal issues among the 'grey literature' (eg websites, news articles, opinion pieces, blogs, etc).

Google has a search "Tools" option on the right hand side that you can use to refine the search according to the various options, including time frames. The advanced search options allows you to refine the search significantly in a manner that is a little easier than using Boolean operators alone.

Google can also be used to search for journal articles. More refined searches for articles journal and books can be made using the Google Scholar search engine (<https://scholar.google.com.au/>). Google Scholar also allows a search of case law – however this is for US Courts only.



3.4. Online Encyclopedias

Most people are now familiar with the concept of Wikipedia (<https://www.wikipedia.org/>) as an online encyclopaedia. Contributions to the various articles are contributed by the community and therefore are not always necessarily accurate.

In the early years of Wikipedia, the topic of Chronic Fatigue Syndrome was in constant dispute as various schools of thought actively tussled over the content of the page

Current information is well referenced and does give a sufficient understanding of the condition and research in the area.



Another quality option is MEPedia (<https://me-pedia.org/>) which provide multiple topics relevant to ME/CFS.



As with Wikipedia, the entries are made by the community and are therefore limited in terms of accuracy and thoroughness. These entries can be useful to understanding a topic and finding articles and other information of relevance to the topic. Caution must be exercised accordingly.

Searching these pages can be effected using simple search terms, quotation marks and Boolean Operators.

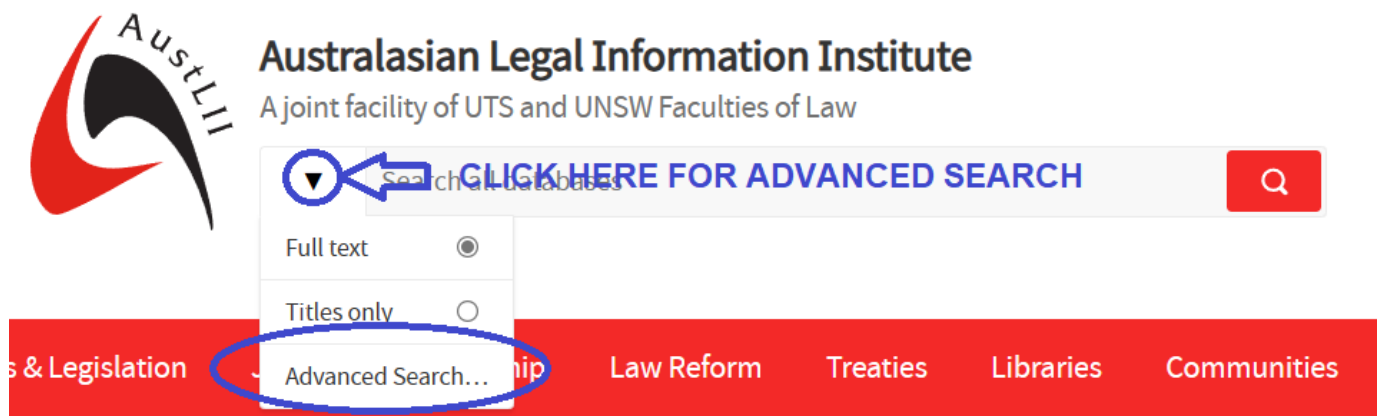
3.5. Austlii

Austlii (www.austlii.edu.au) is a very effective and simple-to-use legal tool for searching Australian case law relevant to ME/CFS.



However, Austlii is more complex than the previous search engines. There are multitude of database sources ranging across State and federal jurisdictions, as well as various secondary sources (eg articles) available. Databases exist for legislation and case law. Given the nature of Australian law, there are multiple court levels, tribunals and commissions, hence a database exists for each of these forums.

Figure 2 - Austlii Advanced Search Option



Austlii has an advanced search option (**Figure 2**) that allows for more specific search options (**Figure 3**).

Figure 3 - Conducting an Advanced Search in Austlii

You can refine a search by date (**Figure 4**) with the most current cases appearing first in the results list. Initial results will include all case law across various databases.

Figure 4 - Conducting Austlii Search and Sort by Date



You can refine a search to a specific database (eg Administrative Appeals Tribunal) so that you only receive AAT case law.

Austlii requires time and repeated searches to work out the way to best obtain the results that you want.

3.6. Other Sources

There are other databases that exist with respect to various jurisdictions and countries.

Worldlii (<http://www.worldlii.org/>) for example, can allow you to access other countries and their case law and legislation.



Worldlii, like Austlii, has tools for refining searches, and various databases from which to choose, including links to other countries. This requires exploration and conducting trial and error searches.

Within various universities, students, staff and alumni alike usually have access to the Library system and therefore the various databases for law and other disciplines. Databases like Westlaw, Jade and LexisNexis can allow access to caselaw that is not available on Austlii, for example.

Older cases, or district court cases, for example, tend not to be available elsewhere, so accessing these databased can open up the older case law.

As outlined above, Google Scholar does allow access to some of the US case law and again, this requires playing with search terms in order to achieve your goals.

Case law in other jurisdictions can assist in understanding the pitfalls of people with ME/CFS in cases, as well as the ways in which they have succeeded.



4. LONG-COVID

4.1. A New Problem

The advent of Covid-19 in early 2020 brought with it a new public health issue that cuts across the full gamut of legal issues that are experienced by people with ME/CFS. Long-Covid, however, brings with it some specific issues that need to be considered by those impacted



4.2. Diagnosis

Like ME/CFS, Long-Covid should be a diagnosis of exclusion. The literature demonstrates that for many, there are identifiable pathologies that cause the symptoms that they are experiencing. This may, for example, include lung scarring, clots, kidney damage, cardiac damage, brain damage, etc.

As with ME/CFS there is an evolving attitude towards the condition whereby medical practitioners are not referring patients to specialists for further investigations. This is in part due to a lack of knowledge and in part due to the same attitude that prevails in ME/CFS – that the symptoms are not real.

A number of long-covid clinics have already been created, with the approach being focused on behavioural attributions and a focus on exercise.

Where that pathology accounts for the symptoms a diagnosis should be made. A failure to refer and a failure to identify such pathology is arguably, medical negligence. It is not appropriate for a medical practitioner to ignore the patient and assume that the symptoms are merely Long-Covid and/or psychosomatic in nature – or even Post Viral Fatigue Syndrome. They should and must investigate.



4.3. Accessing Information

Long Covid Information is now available online in Australia and overseas. The quality of that information varies.

Some people have taken to community Facebook groups, for example, asking about Long-Covid medical assistance, only to be attacked by vile trolls, or referred to information that is far from medical, or helpful.

In Australia, a reasonable source of information may be obtained by joining the Australian Long Covid Community



(<https://www.facebook.com/groups/301101014574843/>) Facebook Group.

More information is available from the group website (<https://www.longcovidsupportaustralia.com.au/>),

4.4. Diagnosing ME/CFS

Much has been made about the similarities between Long-Covid and ME/CFS. With Long-Covid (being a diagnosis of exclusion following the viral illness), the sufferer meets the diagnosis of Post-Viral Fatigue Syndrome (PVFS). PVFS is the classification under which ME/CFS falls within the International Classification of Diseases.

For the purposes of the NDIS, DSP and insurance, the diagnosis of ME/CFS may make the pathway to benefits more accessible than the diagnosis of Long-Covid because of the uncertainty of the condition.

4.5. Accessing Insurances

As with ME/CFS people with Long-Covid often overlook the benefits that are available to them. Whether it be insurances through your superannuation (eg TPD or income protection), personal insurances (eg TPD, income protection, business expenses insurance, key man insurance) or debt insurances (eg mortgage insurance, credit card insurance, loan insurance) – people may have a claim to assist them financially.



4.6. Workers Compensation

During the height of Covid, there were many professions where exposure to Covid was high. Some jurisdictions, such as New South Wales, for example, introduced a presumption that a Covid infection arose from exposure within their occupation (eg Doctors, nurses, teachers, first responders). This presumption was removed over a year ago.

Some people who have Long-Covid may well have a Workers Compensation claim. Such people should make inquiries with a solicitor. Often there is no cost to the Workers Compensation process, depending on jurisdiction.

For those who acquired Covid at a workplace where no presumption existed, the potential for Workers Compensation for Long-Covid still exists where they can establish the infection more than likely originated in the workplace. Again, advice from a Workers Compensation solicitor is recommended.

As with ME/CFS, not all solicitors will understand the condition. Good research and calling around to various firms will help to find those with experience.

4.7. Lessons Learned

ME/CFS Legal Resources provides information that can be applied to those with Long Covid. The political issues at play, the vested interests and the attitude of the medical profession closely resemble the experiences of ME/CFS for the past 40 years, and as such much can be learned from the legal issues in ME/CFS for those with Long Covid.

As Long-Covid issues work their way through the Courts, Tribunals and Commissions that exist, more lessons can be gleaned to guide future disputes.



DISCLAIMER

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