

PRIVACY POLICY

ME/CFS Australia Inc is committed to providing quality services. This policy outlines our ongoing obligations in respect of how we manage all Personal Information.

We abide by the Australian Privacy Principles (APPs) contained in the Privacy Act 1988 (Commonwealth). The APPs govern the way in which we collect, use, disclose, store, secure and dispose of Personal Information. A copy of the Australian Privacy Principles may be obtained from the website of The Office of the Australian Information Commissioner at www.aaic.gov.au.

What is Personal Information and why do we collect it?

Personal Information is information or an opinion that identifies an individual. Examples of Personal Information we collect include names, addresses, email addresses and phone numbers.

This Personal Information is obtained in many ways including membership application/renewal forms, correspondence, and by telephone or email.

We collect your Personal Information for the primary purpose of providing our services to you. We may also use your Personal Information for secondary purposes related to the primary purpose, in circumstances where you would reasonably expect such use or disclosure. This Personal Information will not be used for marketing.

When we collect Personal Information, we will, where appropriate and where possible, explain to you why we are collecting the information and how it will be used.

Sensitive Information

Sensitive information is defined in the Privacy Act to include information or an opinion about such things as an individual's racial or ethnic origin, political opinions, membership of a political association, religious or philosophical beliefs, membership of a trade union or other professional body, criminal record or health information.

Sensitive information will be used by us only:

- for the primary purpose for which it was obtained
- for secondary purpose that is directly related to the primary purpose
- with your consent or where required or authorised by law.

Third Parties

Where reasonable and practicable to do so, we will collect your Personal Information only from you. However, in some circumstances we may be provided with information by third parties. In such a case we will take reasonable steps to ensure that you are made aware of the information provided to us by a third party.

Disclosure of Personal Information

Your Personal Information may be disclosed in the following circumstances:

- third parties where you consent to the use or disclosure
- where required or authorised by law.

Security of Personal Information

Your Personal Information will be stored in a manner that reasonably protects it from misuse, loss, unauthorised access, modification or disclosure.

When your Personal Information is no longer needed for the purpose for which it was obtained, we will take reasonable steps to destroy or permanently de-identify your Personal Information. However, most of the Personal Information is required to be stored in client files which will be kept by us for a minimum of two years.

Access to your Personal Information

You may access the Personal Information we hold about you to update and/or correct it, subject to certain exceptions. If you wish to access your Personal Information, please contact us in writing.

ME/CFS Australia will not charge any fee for your request.

To protect your Personal Information, we will require identification from you before releasing the requested information.

Maintaining the Quality of your Personal Information

It is important to us that your Personal Information is kept current. We will take reasonable steps to make sure that your Personal Information is accurate and complete. If you find that the information we have is not up to date or is inaccurate, please advise us as soon as practicable so we can update our records and ensure we can continue to provide quality services to you.

Policy Updates

This Policy may change due to updates in requirements and is available on our website.

Privacy Policy Complaints and Enquiries

If you have any queries or complaints about our Privacy Policy, please contact us at:

info@mecfs.org.au OR Postal Address:

ME/CFS Australia Ltd,
PO Box 6176,
Upper Mount Gravatt, QLD, 4122
Australia

REVIEW

accepted 30/6/23, reviewed 30/10/24, next review 6/2025

TERMS OF USE

1. TERMS OF USE

- i. ME/CFS Australia Inc (ABN 23088896299) ("us", "we" or "our") owns, operates and controls the website located at <https://mecfssa.org.au> (the "Website").
- ii. A reference to "you" or "your" in these Terms of Use is a reference to any person accessing or using the Website.
- iii. By accessing and using the Website, you agree to these Terms of Use.
- iv. We reserve the right to make changes to these Terms of Use from time to time at our discretion. Amendments will be effective immediately upon notification on the Website. Your continued use of the Website following any such changes will represent your agreement to be bound by the Terms of Use as amended.
- v. References to "Website" in these Terms of Use include any current or future version Website.

2. ACCESS TO AND USE OF THE WEBSITE

- i. From time to time, we may (at our discretion) (i) restrict access to some or all parts of the Website, or (ii) withdraw or amend the information or content on the Website, including but not limited to images, text, design, sound and video files, logos, documents, and downloadable content on the Website (together the "Information"). We will not be liable if for any reason the Website is unavailable at any time or for any period.
- ii. Unless stated otherwise, you are permitted to use and/or reproduce the Information for educational purposes, provided that:
 - a. the Information is used in a personal, non-commercial setting;
 - b. the Information is not altered;
 - c. you do not remove any copyright and/or trademark notices contained in the Information; and
 - d. an acknowledgment of ME/CFS Australia Inc is prominently displayed in connection with the Information.
- iii. You must not use the Website for any illegal, fraudulent, harmful, or malicious purpose. You must not hack into any aspect of the Website, corrupt data, cause annoyance to other users, infringe upon the right of any other person's proprietary right, use the Website to commit or encourage a criminal offence, send any unsolicited advertising or promotional material, or attempt to affect the performance or functionality of any computer facilities accessed through the Website. Breaching this clause 2.2 may constitute a criminal offence and we reserve our rights to report any such breach to relevant law enforcement authorities.

3. INFORMATION ON WEBSITE NOT MEDICAL ADVICE; DISCLAIMER OF LIABILITY

- i. The Information on the Website does not constitute medical or professional services advice and is provided for general educational and informational purposes only.
- ii. The Information does not take into account any individual personal circumstances and should not be used as a substitute for advice from a qualified healthcare professional. Individuals must consult their healthcare professional(s) about individual medical conditions and must not use the Website to treat or diagnose your own or another person's medical condition.
- iii. If you are a healthcare professional, any diagnosis and/or treatment decisions should be made (i) based on your professional investigations and opinions, (ii) using your own professional skill and judgement, and (iii) in compliance with all applicable laws, regulations and codes of practice. You should not construe any of the Information as an endorsement by us of any strategy, recommendation, treatment, action, or application of medication.
- iv. While we make every attempt to ensure the Information is accurate, current and complete, you should consider the Information carefully and use the Information at your own risk. Information on past, current or future research or potential treatment relating to Myalgic Encephalomyelitis/Chronic Fatigue Syndrome is continuously subject to change and the

Information is provided solely on an "as is" and "as available" basis. Subject to any non-excludable consumer guarantees and other consumer protection provisions set out in the Australian Consumer Law, the material displayed on the Website is provided without any guarantees, conditions, or warranties as to its accuracy.

- v. To the full extent permitted by law, we will not be liable for any losses, injuries, claims, liabilities, damages or expenses arising from your use of or reliance on the Information or any error or omission on the Website.
- vi. If you breach any of these Terms of Use or if you misuse the Website, you agree to defend, indemnify and hold harmless us and our representatives from any and all loss and liability including costs and expenses that arise out of or are related to your breach or misuse.
- vii. Nothing in these Terms of Use excludes, limits or modifies your rights under Australian Consumer Law.

5. LINKING TO THE WEBSITE; THIRD PARTY WEBSITES

- i. You may provide or establish links to the Website, so long as such links (i) are compliant with all applicable laws (ii) do not damage our reputation, and (iii) do not suggest any form of association, approval or endorsement by us where none exists.
- ii. The Website may contain links to other websites which are owned, operated and controlled by third parties ("Third Party Website"). We assume no responsibility for the content, practices or availability of any Third Party Website or for any loss or damage that may arise from your use of or reliance on Third Party Websites. We will not be liable for any information, products or services that are published on or may be accessible from Third Party Website and any links to Third Party Websites should not be interpreted as our association with, or endorsement or recommendation of those Website or their content. You are responsible for reading the terms and conditions and privacy policies of any Third Party Websites you visit.

6. INTELLECTUAL PROPERTY

- i. 6.1 All Information made available on the Website is the property of us and the Website's creators. We reserve all intellectual property rights in connection with the Information and/or Website.
- ii. 6.2 Save as provided by clause 2.2 above, you are not permitted to publish, manipulate, distribute, or otherwise reproduce, in any format, any of the Information without our prior written consent.

7. PRIVACY

- i. Our privacy policy, which forms part of these Terms of Use, is available at [<https://mecfsa.org.au/docs/MECFS-Governance/Policies/Privacy-Complaints-Terms-of-Use.pdf>] and provides further information on how we collect, use, hold and disclose personal information, how to request access to and correction of your personal information, how to complain if you believe we have mishandled your personal information and how we will handle your complaint.
- ii. The Website uses various technologies, such as cookies, to ensure you get the best experience on the Website, personalise Information, provide social media features and analyse our traffic. By browsing our website, you consent to our use of cookies. You can configure your browser or device to reject and delete cookies. If you choose to do so, this may limit the functionality of some parts of the Website. For more information, please refer to our privacy policy available at the address above.

8. GENERAL

- i. Severability: If any part of these Terms of Use is unenforceable, the enforceability of any other part of the Terms of Use will not be affected and all other clauses remain in full force and effect.
- ii. Jurisdiction and Governing Law: These Terms of Use are governed by the laws of the Australia. The courts of Australia shall have non-exclusive jurisdiction over any dispute

arising out of your use of the Website or these Terms of Use and you hereby submit to the jurisdiction of the courts of Australia.

- iii. Termination of use: You may stop using the Website at any time for any reason. We reserve the right in our absolute discretion (acting reasonably) to suspend or terminate your access to the Website at any time without notice.
- iv. No waiver: Any failure by us to enforce or exercise a right conferred upon use by the Terms of Use immediately will not be considered a waiver of our right to take any such action.

9. CONTACT US

- i. If you have any questions or concerns about these Terms of Use, the Website or the Information, please contact us at info@mecfs.org.au.

REVIEW

Accepted: 6/2025 review: 6/2027

Complaint Handling Policy

Purpose

ME/CFS Australia seeks to provide a safe and effective process for those who wish to make a complaint. Complaints and compliments are best viewed as a positive interaction with the people we serve.

We aim to have good complaint handling so that we can:

- Improve our services
- Build better relationships with our members
- Empower our volunteers to resolve issues fairly and efficiently

This policy is intended to ensure that we handle complaints fairly, efficiently and effectively.

This policy provides guidance to our volunteers and people who wish to make a complaint on the key principles and concepts of our complaint management system.

Scope

This policy applies to both formal and casual volunteers and employees/contractors of ME/CFS Australia. References to volunteers should be read as including employees and contractors.

Organisational commitment

This organisation expects volunteers at all levels to be committed to fair, effective and efficient complaint handling. The following table outlines the nature of the commitment expected from volunteers and the way that commitment should be implemented.

ROLE: Executive officers of the governing body	Promote a culture that values complaints and their effective resolution
	Report to the governing body on our complaint handling.
	Regularly review reports about complaint trends and issues arising from complaints.
	Encourage volunteers to make recommendations for system improvements.
	Provide adequate support and direction to key volunteers responsible for handling complaints.
	Encourage all volunteers to be alert to complaints and assist those responsible for handling complaints to resolve them promptly.
	Support recommendations for service, volunteers and complaint handling improvements arising from the analysis of complaint data.
All volunteers	Be aware of our complaint handling policies and procedures.
	Understand and comply with our complaint handling practices.
	Be alert to complaints and assist volunteers handling complaints to resolve matters promptly
	Treat all people with respect, including people who make complaints.
	Assist people who wish to make complaints to access our complaints process.

Terms and Definitions

Complaint

An expression of dissatisfaction made to or about us, our services, volunteers or the handling of a complaint where a response or resolution is explicitly or implicitly expected or legally required. (AS/NZ 10002:2014).

As well as complaints being made directly to our organisation, remember that some complaints (or at least negative comments) may be made on social media.

Complaint handling/management system

All policies, procedures, practices, volunteers, hardware and software used by us in the management of complaints.

Dispute

An unresolved complaint escalated either within or outside of our organisation.

Feedback

Opinions, comments and expressions of interest or concern, made directly or indirectly, explicitly or implicitly, to or about us, about our services or complaint handling system where a response is not explicitly or implicitly expected or legally required.

Grievance

A clear, formal written statement by an individual volunteer member about another volunteer member or a work-related problem.

Policy

Guiding principles

1. **Facilitate complaints:** An effective complaint handling system must be modelled on the principles of fairness, accessibility, responsiveness, efficiency and integration into organisational culture.
2. **People focus:** We are committed to seeking and receiving feedback and complaints about our services, systems, practices, procedures, products and complaint handling. Any concerns raised in feedback or complaints will be dealt with within a reasonable time frame.
3. **No detriment to people making complaints:** We will take all reasonable steps to ensure that people making complaints are not adversely affected because a complaint has been made by them or on their behalf.
4. **Anonymous complaints:** We do not accept anonymous complaints unless there is a compelling reason to do so and will carry out a confidential investigation of the issues raised where there is enough information provided.
5. **Accessibility:** We will ensure that information about how and where complaints may be made to or about us is well publicised on our website with the Terms and Conditions. We will ensure that our systems to manage complaints are easily understood and accessible to everyone, particularly people who may require assistance. If a person prefers or needs another person or organisation to assist or represent them in the making and/or resolution of their complaint, we will communicate with them through their representative if this is their wish. Anyone may represent a person wishing to make a complaint with their consent (e.g. advocate, family member, legal or community representative, member of Parliament, another organisation).
6. **No charge:** Complaining to us is free.

Responding to complaints

Early resolution

Where possible, complaints will be resolved at first contact with us.

Level 1 complaints (see below) will involve an attempt to resolve the complaint immediately.

Level 2 and 3 complaints will involve the person making the complaint being:

- provided with information about our complaint handling process and how to access it
 - listened to, treated with respect by volunteers and actively involved in the complaint process where possible and appropriate, and
 - provided with reasons for our decision/s and any options for redress or review.
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- When appropriate we may offer an explanation or apology to the person making the complaint.

Responsiveness

We will promptly acknowledge receipt of complaints.

We will assess and prioritise complaints in accordance with the urgency and/or seriousness of the issues raised. If a matter concerns an immediate risk to safety or security the response will be immediate and will be escalated appropriately.

We are committed to managing people's expectations, and will inform them as soon as possible of the following:

- the complaints process
- the expected time frames for our actions
- the progress of the complaint and reasons for any delay
- their likely involvement in the process, and
- the possible or likely outcome of their complaint.

We will advise people as soon as possible when we are unable to deal with any part of their complaint and provide advice about where such issues and/or complaints may be directed (if known and appropriate).

We will also advise people as soon as possible when we are unable to meet our time frames for responding to their complaint and the reason/s for our delay.

Objectivity and fairness

We will address each complaint with integrity and in an equitable, objective and unbiased manner. Level 1 complaints (see below) may be able to be managed by the person to whom the complaint is made, even when they are the person about whom the complaint is made. For Levels 2 and 3 (see below) we will ensure the person handling a complaint is different from any volunteer whose conduct or service is being complained about.

Conflicts of interest, whether actual or perceived, will be managed responsibly. In particular, internal reviews of how a complaint was managed will be conducted by a person other than the original decision maker.

Responding flexibly

Our volunteers are empowered to resolve complaints promptly and with as little formality as possible. We will adopt flexible approaches to service delivery and problem solving to enhance accessibility for people making complaints and/or their representatives.

We will assess each complaint on its merits and involve people making complaints and/or their representative in the process as far as possible.

Confidentiality

We will protect the identity of people making complaints where this is practical and appropriate. Personal information that identifies individuals will only be disclosed or used by us as permitted under the relevant privacy laws, secrecy provisions and any relevant confidentiality obligations.

Manage the parties to a complaint

Complaints involving multiple agencies

Where a complaint involves multiple organisations, we will work with the other organisation/s where possible, to ensure that communication with the person making a complaint and/or their representative is clear and coordinated.

Subject to privacy and confidentiality considerations, communication and information sharing between the parties will also be organised to facilitate a timely response to the complaint.

Where a complaint involves multiple areas within our organisation, responsibility for communicating with the person making the complaint and/or their representative will also be coordinated.

Where our services are contracted out, we expect contracted service providers to have an accessible and comprehensive complaint management system. We take complaints not only about the actions of our volunteers but also the actions of our service providers.

Empowerment of volunteers

All volunteers managing complaints are empowered to implement our complaint management system as relevant to their role and responsibilities.

Volunteers are encouraged to provide feedback on the effectiveness and efficiency of all aspects of our complaint management system.

Managing unreasonable conduct by people making complaints

We are committed to being accessible and responsive to all people who approach us with feedback or complaints. At the same time our success depends on:

- our ability to do our work and perform our functions in the most effective and efficient way possible
- the health, safety and security of our volunteers, and
- our ability to allocate our resources fairly across all the complaints we receive.

When people behave unreasonably in their dealings with us, their conduct can significantly affect the progress and efficiency of our work. As a result, we will take proactive and decisive action to manage any conduct that negatively and unreasonably affects us and will support our volunteers to do the same in accordance with this policy.

It is expected that those making complaints will behave in a respectful, non-abusive manner.

We operate under the assumption that all complaints are made in good faith and are not motivated by intent for personal gain, personal interest or a grudge. However, should a subsequent investigation reveal a complaint to be malicious or vexatious – an accusation that the complainant knows to be false - any investigation underway must be stopped immediately and the subject of the complaint will be cleared. Complaints lodged for genuine reasons that are subsequently considered to be unfounded shall not be treated as malicious. If a malicious complaint is made by an ME/CFS Australia volunteer, appropriate disciplinary measures will be taken.

Alternative avenues for dealing with complaints

We will inform people who make complaints to or about us about any internal or external review options available to them i.e. Australian Charities and Non-for-Profits Commission

The three levels of complaint handling

Level 1: We aim to resolve complaints at the first level, the frontline. Wherever possible volunteers will be adequately equipped to respond to complaints, including being given appropriate authority, training and supervision.

All level 2 and 3 complaints will be reported to the Board as soon as possible

Level 2: Where this is not possible, we may decide to escalate the complaint to a more senior officer within our organisation. This second level of complaint handling will provide for the following internal mechanisms:

- assessment and possible investigation of the complaint and decision/s already made, and/or
- facilitated resolution (where a person not connected with the complaint reviews the matter and attempts to find an outcome acceptable to the relevant parties).

Level 3: Where a person making a complaint is dissatisfied with the outcome of our review of their complaint, they may seek an external review of our decision by the Australian Charities and Not-for-Profits Commission.

Accountability and learning

Analysis and evaluation of complaints

We will ensure that complaints are recorded in a systematic way so that information can be easily retrieved for reporting and analysis by management and the governing body of Directors.

We will run regular reports on:

- the number of complaints received
- the outcome of complaints, including matters resolved at the frontline
- issues arising from complaints
- systemic issues identified, and
- the number of requests we receive for internal and/or external review of our complaint handling.

Regular analysis of these reports will be undertaken by executive officers to monitor trends, measure the quality of our customer service and make improvements.

Monitoring and continuous improvement of the complaint management system

We will continually monitor our complaint management system to:

- ensure its effectiveness in responding to and resolving complaints
- identify and correct deficiencies in the operation of the system
- monitoring may include the use of audits, complaint satisfaction surveys and online listening tools and alerts.
- support the making and appropriate resolution of complaints
- implement best practices in complaint handling
- recognise and reward exemplary complaint handling by volunteers
- regularly review the complaint management system and complaint data, and
- implement appropriate system changes arising out of our analysis of complaints data and continual monitoring of the system.

Procedure

When responding to complaints, volunteers act in accordance with complaint handling procedures as well as any other internal documents providing guidance on the management of complaints.

Volunteers should also consider any relevant legislation and/or regulations when responding to complaints and feedback.

The five key stages in our complaint management system are set out below

1. Receive

We will record the complaint in the complaints register and its supporting information. We will also assign a unique identifier/number to the complaint file.

The record of the complaint will document:

- Contact information of the person making a complaint and the date received
- Issues raised by the person making a complaint and the outcome/s they want
- Any other relevant information, and
- Any additional support the person making a complaint requires.

2. Acknowledge

We will acknowledge receipt of each complaint promptly, and preferably within 5 working days.

When appropriate we may offer an explanation or apology.

Consideration will be given to the most appropriate medium (e.g. email, letter) for communicating with the person making a complaint.

3. Assess and investigate

Initial assessment

After acknowledging receipt of the complaint, we will confirm whether the issue/s raised in the complaint is/are within our control. We will also consider the outcome/s sought by the person making a complaint and, where there is more than one issue raised, determine whether each issue needs to be separately addressed.

When determining how a complaint will be managed, we will consider:

- How serious, complicated or urgent the complaint is
- Whether the complaint raises concerns about people's health and safety
- How the person making the complaint is being affected
- The risks involved if resolution of the complaint is delayed, and
- Whether a resolution requires the involvement of other organisations.

Investigating the complaint

After assessing the complaint, we will consider how to manage it. We may:

- Give the person making a complaint information or an explanation
- Gather information about the issue, person or area that the complaint is about, or
- Investigate the claims made in the complaint.

We will keep the person making the complaint up to date on our progress, particularly if there are any delays. We will also communicate the outcome of the complaint using the most appropriate medium. Which actions we decide to take will be tailored to each case and consider any statutory requirements.

Should investigation reveal a complaint to be malicious or vexatious – an accusation that the complainant knows to be false - the investigation will be stopped immediately and the subject of the complaint will be cleared. (Complaints lodged for genuine reasons that are subsequently considered to be unfounded shall not be treated as malicious.) If a malicious complaint is made by an ME/CFS Australia volunteer then appropriate disciplinary measures will be taken.

4. Determine outcome and provide reasons for decision

Following consideration of the complaint and any investigation into the issues raised, we will contact the person making the complaint and advise them:

- The outcome of the complaint and any action we took
- The reason/s for our decision
- The remedy or resolution/s that we have proposed or put in place, and
- Any options for review that may be available to the complainant, such as an internal review, external review or appeal.

5. Close the complaint: document and analyse data

We will keep records about:

- How we managed the complaint
- The outcome/s of the complaint (including whether it or any aspect of it was substantiated, any recommendations made to address problems identified and any decisions made on those recommendations), and
- Any outstanding actions to be followed up, including analysing any underlying or root causes.

References:

[Managing Conflicts of Interest ACNC Guides](#)

Review

Accepted 6/25

Next review 2027



The peak body for the patient-led ME/CFS charities across Australia

Advocacy | Education | Collaboration

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