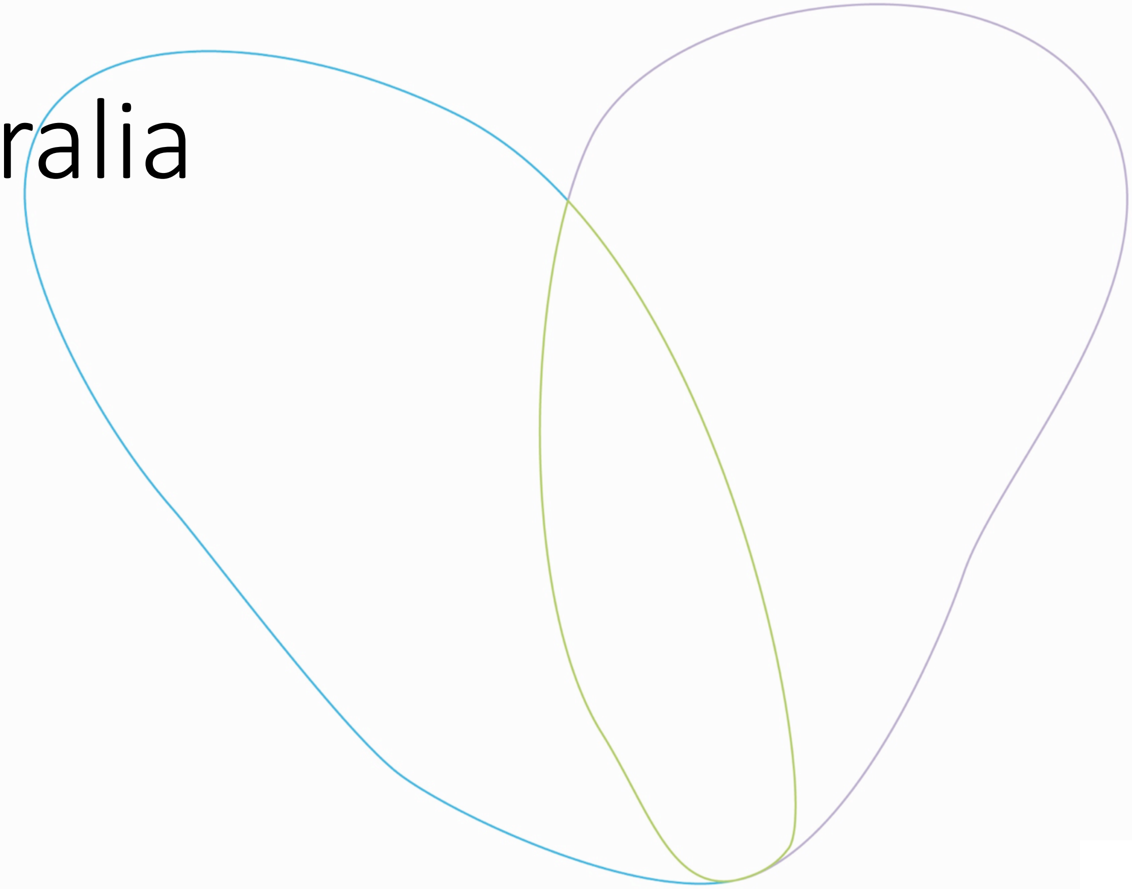
Emerge Australia

Strategic Plan 2021-2024



What are the significant issues to take into account? "What's going on here?"

Lived experience of people with ME/CFS

There is a wide range of severity with this disease, but most people are significantly affected in their ability to live normal lives, require support, have episodic poor health, and associated conditions including mental health issues due to stigma and the long-term effects of disability.

People often go on two "journeys" with this disease. A search for a diagnosis (and cure), followed by a re-framing of their condition to "living with a disability". Carers and family members are often going on a similar journey to the person with ME/CFS.

GPs and most Allied Health workers are not aware of, or trained in, ME/CFS and most are unable to provide the necessary diagnostic and care framework. Therefore, people with this disease have long diagnostic journeys and are desperate for high quality, reliable information.

Many people are disadvantaged due to the economic impact of the disease.

Quick diagnostic tests would benefit people enormously – combined with good GP and specialist understanding.

External environment : Emerge Australia's "eco-system"

ME/CFS is often an invisible condition, with low levels of understanding at political, government and service provider levels which leads to a lack of coordinated services.

There is no clinical test and an insufficient research base for clinical and condition management. In addition to this, the disease receives only low levels of funding.

People suffering from the disease are physically isolated and this limits their ability to lobby and to access services. It also means that online information is prominent, and in an online world all information can look like it has the same legitimacy. The lack of clear up to date government and health guidelines is confusing.

This sector contains a wide range of organisations that have a range of agendas which makes government and other stakeholder engagement more complicated.

A clear evidence based strategy is required in order to influence Government (and the medical and allied health professions) and to more educate the wider community.

Emerge Australia is increasingly seen as the "go to" source for Government and the medical profession.

What are the current focus areas of our work? How are they going? What are the implications for our future strategy?

Current focus area	What's currently happening?	What are the implications for this strategy?
Services	We run a range of services including: first point of contact and information services; newsletter and journal publishing; online community and some events. We provide information on a range of issues including finding medical help, support groups, and NDIS. Our telehealth nursing program expands our ability to answer questions and is primarily used to provide a comprehensive history to help people with medical appointments	One of the biggest questions people have is where they can get good medical support and advice. It is not possible for us to meet this clinical need with our current services – and yet it remains the key question we are asked. Our current clinical services are small in scale. We should either provide more, and do so explicitly, or we should withdraw from this domain
Advocacy	We undertake research into the lived experience of people with ME/CFS which informs our advocacy campaigns. We involve the ME/CFS community, which is both powerful for advocacy and validating for community members	A long term focus on advocacy will maximise the chances of benefits for the ME/CFS community
Education	Activities include: community awareness; media appearances; website; GP education; research digest; fact sheets	This focus area gives us the most "payoff" for the effort expended – and it remains vitally needed. This is one area where there is no real duplication at the national level between us and other groups.
Research	We have embraced a new role of funding medical research through partnering with OMF in order that we don't have to make individual research project decisions. We try to educate patients to be advocates on research funding committees. We have worked to establish the Biobank – so that it is "neutrally" positioned for the whole research sector. Our lobbying for the TCRs helped to secure $3m for research into ME/CFS in Australia	We got involved in medical research – funding partnerships and the Biobank – because no one else was doing it and because there was a strong desire from the community to have a coordinated place to support good biomedical research - from larger philanthropists down to individuals. It was also important to have neutral underpinnings in this domain. Research is vital given the need for quick diagnostic tests for people with ME/CFS

Vision

Australians with ME/CFS achieve the highest quality of life possible

This Vision statement sets out "the transformation we want to make in the world" – effectively, it is the purpose for our organisation

Mission

Every Australian diagnosed with ME/CFS receives effective medical and other services without stigma or discrimination

This Mission statement explains (at the highest level) how we will attempt to achieve our Vision

Change Objectives

- Quick and accurate diagnosis
- Widespread understanding that ME/CFS is a chronic disabling biomedical condition
- Effective treatments that can be readily accessed
- Seamless access to high quality services for people with ME/CFS and their carers

These Change Objectives define what it means to successfully achieve our Vision. As such, they not only define how to measure success, they also start to suggest approaches to achieving change

This Vision statement sets out “the transformation we want to make in the world” – effectively, it is the purpose for our organisation. Our Vision calls for a transformation that is centered around the concept of justice. People with ME/CFS should receive the same standard of care and assistance that anyone else in need receives. This is based on the key assertion that an individual’s rights create responsibilities in the systems that are meant to be supporting them.

We serve people living with ME/CFS. That includes both those people who have the disease as well as their families and carers

We exist to serve Australians living with ME/CFS. This is a deliberate focus on the whole of Australia

Vision

Australians with ME/CFS achieve the highest quality of life possible

We want people with ME/CFS to enjoy the highest quality of life that they can

This Mission statement explains (at the highest level) how we will attempt to achieve our Vision.

*What we want to achieve needs to be accessible to **all** Australians regardless of their social or economic status or any other advantages or disadvantages*

Mission

Every Australian diagnosed with ME/CFS receives effective medical and other services without stigma or discrimination

We hope that effective medical services will include an eventual cure. But we don't want to wait for that. We want medical and other services to be relevant and useful today

Stigma and discrimination too often compound the issues faced by people with ME/CFS in accessing assistance

These Change Objectives define what it means to successfully achieve our Mission and, through it, our Vision. As such, they not only define how to measure success, they also start to suggest approaches to achieving change.

Quick and accurate diagnosis

We want to see a substantial shift from the current situation where most people live with this disease for a number of years before receiving an accurate diagnosis of ME/CFS. An accurate early diagnosis would allow for better symptom management at an early stage, and therefore better disease prognosis. It also allows for some certainty for the person living with ME/CFS and for their carers and families.

Long term key results

- Consensus within the medical profession and researchers on name and criteria for diagnosis
- Clinical guidelines in Australia up to date and fit for purpose (eg not referencing discredited treatments such as Graded Exercise Therapy or treatments without a sufficient evidence base)
- Widespread knowledge of the diagnostic criteria for ME/CFS amongst GPs and specialists
- Ability to access an accurate diagnosis without systemic delays
- Co-morbidities identified, other potentially causative conditions excluded

Widespread understanding that ME/CFS is a chronic disabling biomedical condition

We want the broad community and the medical profession to have a substantially increased understanding that ME/CFS is a complex, chronic, disabling condition with a biomedical cause. This change in understanding amongst the community and doctors will have a substantial impact on the quality of life of people with ME/CFS.

Long term key results

- Reduced stigma of ME/CFS in the medical profession
- Widely available education and communication resources
- Wide discussion in the media combined with acceptance and understanding of the biological basis of ME/CFS
- Acceptance of ME/CFS into a single medical college
- ME/CFS is recognised as a disability in terms of the provision of community and government services and agencies

These Change Objectives define what it means to successfully achieve our Mission and, through it, our Vision. As such, they not only define how to measure success, they also start to suggest approaches to achieving change.

Effective treatments that can be readily accessed

We want to see treatments available that are effective at tackling symptoms and restoring people to health. These need to be evidence based and widely available.

It's important that people with ME/CFS receive integrated treatments, addressing their wide range of symptoms. These treatments also need to be ongoing given the current chronic nature of the disease.

Long term key results

- Evidence based treatments that have real efficacy (and can address the wide range of symptoms of ME/CFS) are readily accessible by people with ME/CFS on a timely and equitable basis
- Widespread understanding of clinical guidelines and treatment options amongst GPs and specialists
- Integrated care centred around the lived experience of the patient is readily available

Seamless access to high quality services for people with ME/CFS and their carers

Seamless access to high quality services is vital for the effective provision of treatments.

We want to see a coordinated system of care, support, and information services seamlessly available to people living with ME/CFS and their carers and families. This coordinated system should operate in much the same way as similar services for people living with other diseases (such as MS or cancer).

Long term key results

- A coherent suite of services are on offer (from us and others) in the following categories:
  - Support groups and forums
  - Events and community building
  - Self-management information and skill building (where appropriate)
  - Ability to access support services (including NDIS, DSP, and others)

Key Focus Areas

To succeed our strategy needs to be implemented effectively. The best way to do this is to concentrate our efforts in seven Key Focus Areas. The delivery of these seven Key Focus Areas will drive the achievement of our four "change objectives" above.

	🔍	❗	✚	⚷
① Services		✓		✓
② Education and Awareness		✓		
③ Research	✓		✓	
④ Clinical	✓		✓	
⑤ Advocacy and Policy			✓	✓

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⑥ Financial Sustainability

⑦ Staff and capability development

🔍 *diagnosis*

❗ *understanding*

✚ *treatments*

⚷ *services*

① Services

Emerge Australia recognises that we will not meet our community's needs or achieve our Vision and Change Objectives by trying to provide all the services that people with ME/CFS need. Our role is to drive systemic change by example, by using our voice, and through our credibility. Our approach to providing services will be informed by this insight. We will provide services that support our community and also that help us to understand and connect with them - in order to best serve them.

We will continue to invest in the Info Line with the aim for it to provide:

- *A strong first impression and "relationship commencement"*
- *Immediate answers to questions and a "setting of expectations" for people newly diagnosed*
- *Connections with other services Emerge Australia chooses to provide*
- *Referrals to trusted third parties*

We will apply the following principles when deciding what services to provide:

- *Will it meet an unmet need?*
- *Will the service have a high impact?*
- *Will the impact be measurable?*
- *Will funding be readily available?*

	✓		✓

What we are aiming to achieve by 2024:

People living with ME/CFS, and their carers and families, have more seamless access to a wider suite of services (provided by us and other organisations) that address a better range of their non-clinical needs in a coherent and easy to navigate fashion.

② Education and Awareness

Emerge Australia, working with others (nationally and internationally), will use our position in the community and established relationships to drive a substantial raising of awareness, understanding, and knowledge of ME/CFS in the broad community, in Government, and in the medical profession.

Education and Awareness is a vital focus area providing us with a lot of leverage:

- *We will continue to build programs that educate the medical profession*
- *We will develop further community education initiatives including maintaining and developing our website, fact sheets, social media and mainstream media presences*

This focus area is principally aimed at delivering our "widespread understanding" change objective. Nonetheless, we recognise that, done well, this focus area will have impacts on the other three change objectives as well.

Over the next three years we will prioritise this education focus area because we believe that education is the best form of advocacy we can undertake.

✓

What we are aiming to achieve by 2024

A substantial raising of awareness, understanding, and knowledge of ME/CFS in the broad community and in the medical profession.

Improved guidelines and improved service provision for people with ME/CFS from key agencies.

③ Research

Emerge Australia will support research in Australia into the bio-medical basis for ME/CFS through: fundraising; linking patients to research projects; and maintaining the biobank and registry. We will build excellent relationships with research groups in Australia and overseas.

Our aim in pursuing research is two-fold:

- *To enable the discovery of bio-markers and other diagnostic indicators of ME/CFS*
- *To find treatments that will increase the quality of life of people living with ME/CFS*

A vital part of our approach will be through delivering and building effective partnerships with key groups and researchers. Our current partnerships include OMF, Solve ME/CFS, CURE ME (UK Biobank), Menzies Institute at UTAS, Deakin University, Macquarie University and others.

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What we are aiming to achieve by 2024

- Increased levels of funding for the highest quality biomedical and translational research into ME/CFS in Australia, leading to improved diagnosis, treatment and quality of life
- Strong outcomes from our partnership with OMF, including significant published results that have an impact on the lives of people with ME/CFS
- The biobank and registry will be on a sustainable footing, supported by strong partnerships with the research community
- The number of researchers working in the field of ME/CFS in Australia is substantially increased

④ Clinical

We will continue to invest in the TeleHealth Nurse program and the GP Education programs to help lift the standard of care and advice given to people with ME/CFS and their carers.

We aim to continue to build our clinical capability over the coming years. In particular, over the next ten years Emerge Australia is committed to developing a clinical centre of excellence into ME/CFS in Australia.

We will develop this centre for two reasons:

- *The most common query that Emerge Australia receives is how to find knowledgeable qualified experts in ME/CFS. There are currently no, or very few, appropriately qualified experts who we can refer people to.*
- *The medical profession will benefit enormously from having specialised knowledgeable clinicians to refer patients to and who can develop guidelines on ME/CFS*

We therefore need to develop a clinical capability in Australia – underpinned by good governance and oversight. To do this well we will need to scope the project and prototype it, while considering the appropriate structuring and compliance options.

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What we are aiming to achieve by 2024

- The clinical care for Australians with ME/CFS is improved
- There is a clear description of the clinical centre of excellence model to be built – supported by a sound business case and robust funding pathway

5 Advocacy and Policy

We will undertake advocacy campaigns to change policy primarily at Federal or national level and, where possible and appropriate, at State level. We recognise that policy has a direct impact on the quality and availability of support services and treatments for people living with ME/CFS.

At its core our advocacy efforts will consist of clearly articulating the public policy and clinical health need on behalf of people living with ME/CFS and holding key stakeholders to account for provision and delivery of high quality services appropriate to the level of need within this community. We acknowledge that Emerge Australia cannot provide every service needed.

Our advocacy role is to put pressure on other funded agencies to deliver on their responsibilities to people with ME/CFS who have an equal right to high quality service provision in health, education, financial support etc.

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What we are aiming to achieve by 2024

- Our work is recognised as playing a material role in improving the clinical and non-clinical experiences and supports of people with ME/CFS and their families and carers
- Advocacy focuses for campaigns and lobbying over the next three years:
    - Update of clinical guidelines
    - Improved consensus on name and diagnostic criteria
    - Acceptance of ME/CFS into a single medical college
    - Better inclusion of people with ME/CFS in employment and study
    - Better funding for biomedical research
- Encouragement of unified voice for ME/CFS organisations in Australia and New Zealand especially on key policy positions

⑥ Financial sustainability

Pursue initiatives to place the organisation on a sustainable financial footing.

Continued work to secure research funding tied to high quality projects aimed at better treatments and diagnosis. Expanding this work to include significant projects such as the centre of clinical excellence and other service delivery needs.

Securing a greater level of untied funding that can be used to support the work of the organisation, including advocacy and education work.

What we are aiming to achieve by 2024

- Fundraising capability and strategy in place and delivering substantial results
- Diversified ongoing revenue base
- Successfully put in place limited cost recovery on a small number of programs

⑦ Staff and capability development

Ensure we have the right number of staff, with the right skills, configured in the right way to carry out this strategy. Ensure we have supportive systems and processes in place in a sustainable way.

Continue to sustain a supportive, happy and engaged culture for staff and volunteers.

Support staff to develop knowledge and capability to work in flexible and new ways. Support successful remote working with staff, supporters and suppliers.

What we are aiming to achieve by 2024

- We have used our learnings from 2020 to embed best practice ways of remote working to ensure that we can continue to support people with ME/CFS
- Successful staff plans/projects implemented and ongoing:
    - Onboarding
    - Learning and development
    - Team building/culture
- Systems that support the delivery of the strategy:
    - CRM
    - IT systems
    - Financial processes
    - Governance
    - Risk management
    - Ongoing monitoring, evaluation and learning