



# Mission and Values

5th March 2026

*Stronger Together*

## 1. Mission Statement

Forward-ME brings together national charities, support groups and campaigning organisations to improve the lives of people with myalgic encephalomyelitis (ME). We work collaboratively to influence research, clinical practice, policy, education and public understanding, ensuring that the needs—including those of the most severely affected—are heard, respected and acted upon.

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## 2. Values and Principles

Forward-ME and its member organisations commit to the following shared values:

### **Collaboration**

We work together openly and constructively, recognising that our collective impact is greater than the sum of our individual efforts.

### **Integrity and Transparency**

We act honestly, ethically and in the best interests of people with ME, communicating clearly and maintaining transparency wherever possible. (People with ME include people living with and/or affected by Myalgic Encephalomyelitis (ME) and related or co-morbid conditions and will be referred to as ME throughout this document).

### **Respect and Inclusion**

We value the diverse experiences and perspectives within the ME community, ensuring that all voices—including those who are severely or very severely affected and children and young people—are represented and respected.

### **Evidence and Excellence**

We champion high-quality scientific research, evidence-based practice, and the accurate implementation of clinical guidelines.

## **Empowerment**

We seek to empower people with ME and their families by promoting understanding, recognition and equitable treatment.

## **Accountability**

We take responsibility for our actions and commitments, and we work to maintain trust within the ME community and beyond.

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# **3. Aims for Member Organisations**

Member organisations of Forward-ME agree to work collectively to:

1. **Support the full and accurate implementation of NICE Guideline NG206**, promoting its adoption across healthcare, social care and relevant sectors.
  2. **Act in the best interests of Forward-ME**, contributing constructively to its mission, discussions and collaborative projects.
  3. **Advance the interests of people living with ME** in research, clinical service delivery, policymaking, education and public awareness.
  4. **Ensure the voice of people severely and very severely affected by ME is central** to Forward-ME's work, shaping decisions and advocacy.
  5. **Promote effective collaboration and communication** between national charities, support groups and campaigning organisations.
  6. **Coordinate joint actions where appropriate**, including research engagement, policy responses, advocacy efforts, and public communications.
  7. **Strengthen the visibility, credibility and influence of Forward-ME**, helping amplify shared messages and engage with external stakeholders.
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## 4. Membership Criteria for Organisations

To become and remain a member of Forward-ME, an organisation or individual should:

1. **Be a national charity, national non-governmental organisation or campaigning group**, or an individual, with a demonstrable commitment to and track record of improving the lives of people with ME.
  2. **Align with the mission, values and aims of Forward-ME.**
  3. **Agree to the Code of Conduct** and participate in shared activities in good faith.
  4. **Demonstrate an evidence-based, ethically sound approach** to ME research, advocacy, information sharing and support.
  5. **Show respect for people with ME**, including those severely affected, in all public and internal communications.
  6. **Contribute meaningfully to the collaborative work** of Forward-ME (e.g., through attendance, sharing expertise, supporting joint initiatives).
  7. **Commit to transparency**, particularly regarding organisational goals, funding sources and key activities.
  8. **Avoid conflicts of interest**, and declare any relevant potential conflicts to the group.
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## 5. Code of Conduct for Member Organisations

Member organisations agree to uphold the following standards:

### Commitment to Collaboration

- Engage constructively and courteously with other members.
- Share knowledge, expertise and relevant resources where possible.

### Respectful Communication

- Maintain respectful dialogue, recognising differing perspectives.

- Avoid disparaging other member organisations or individuals.

## **Evidence-based Practice**

- Ensure that information, statements and advocacy positions are accurate and grounded in credible evidence, including NICE Guideline NG206.

## **Representation of the ME Community**

- Ensure communications and decisions respect the experiences of people living with ME, particularly those severely affected.
- Avoid tokenism and actively ensure inclusive representation.

## **Confidentiality**

- Respect the confidentiality of discussions held within Forward-ME, unless agreement is reached to share information externally.

## **Professional Conduct**

- Act with integrity, honesty and ethical awareness.
- Address disagreements constructively and through agreed channels.

## **Support for Forward-ME Activities**

- Participate in meetings, consultations and joint actions to the best of the organisation's ability.
- Promote Forward-ME publicly when appropriate and help maintain a positive reputation.

## **Responsibility and Accountability**

- Organisations are bound by their charitable objectives and governance structures. Wherever possible organisations will follow Forward-ME policies and decisions once agreed, or will make any divergence from this known to the other members.
- Address any breaches of this Code promptly and constructively.



# Governance Document

5th March 2026

## 1. Name

The name of the organisation shall be **ForwardME** (hereinafter referred to as “the Body”).

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## 2. Status and Legal Form

ForwardME is a **non-charitable umbrella organisation**. It operates as a **voluntary, unincorporated association** under the laws of England and Wales.

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## 3. Aims and Objectives

### 3.1 Core Aim

To coordinate, support, and represent the collective voice of UK charities, non-governmental organisations (NGOs), and campaigning bodies working on behalf of people living with and affected by Myalgic Encephalomyelitis (ME) and related or co-morbid conditions (referred to as ME throughout this document). In doing so, it aims to strengthen the collective voice of people with ME by enabling cooperation and coordination between organisations that represent or support them.

### 3.2 Objectives

ForwardME shall:

- Promote co-ordination, **collaboration** and **shared strategic planning** between member organisations. "ForwardME does not replace member organisations - it helps them work together more effectively."
- Advocate for **improved recognition, research, and understanding** of ME within healthcare, education, research, and public policy.
- Support efforts to **improve services and outcomes** for people living with and affected by ME.
- Facilitate the **exchange of information** and best practice among member bodies.

- Represent the **collective views** of the member organisations in dialogue with government, research funders, healthcare providers, the community of people affected by ME and the wider public.
  - Support the development of **evidence-based policy** and practice.
  - Contribute to promoting **greater accurate public awareness** of ME.
  - Encourage inclusivity, transparency, and patient involvement in all activities - **'Nothing about us without us'**.
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## 4. Membership

### 4.1 Eligibility

Membership is open to:

- UK-registered charities, non-profit organisations, or campaigning bodies whose principal aim is to improve the lives of people with ME.
- Individuals including researchers, clinicians and health care professionals who have a proven track record of advocating for the needs of people living with ME whose contribution would enhance the aims of Forward ME and strengthen its activities.
- In approving new members, either organisations or individuals, consideration will be given to ensuring greater diversity so that there is a voice for groups historically under-represented in advocacy for example those severely affected, children and young people, people from BAME communities and others.
- The facilitator of each sub-group if not in one of the two categories above.
- Non named members of ForwardME committee can be invited to join a sub group on the understanding they are not full members of ForwardME but should abide by the standards set out in this governance document

### 4.2 Application

- Organisations and individuals shall apply for membership in writing to the administrator.
- Applications will be reviewed by the Admin Group and approved at the next timely main meeting (with notice on the agenda). If an objection re the applicant is raised at the meeting, the application will be reviewed by the admin group and a discussion with the objector had. If an outcome cannot be reached through discussion a vote will take place at the next main meeting, a 75% majority is needed to accept or deny a membership.

### 4.3 Obligations

All member bodies must:

- Endorse and abide by the aims and objectives of ForwardME;
- Nominate up to two representatives to participate in meetings and where appropriate use their organisation's vote; and
- Maintain up-to-date contact details and ensure active participation.

All members and representatives are expected to:

- Act collaboratively and respectfully towards other members;
- Uphold the values of collaboration, respect, and evidence-based practice;
- Declare any conflicts of interest;
- Maintain confidentiality, the issues discussed at meetings may be shared to others (unless stated they are confidential), but details of the discussion or "who said what" should not be shared outside of the meeting; and
- Avoid actions that bring ForwardME or member organisations into disrepute.

## 4.4 Termination of Membership

Membership may be suspended or terminated by resolution of the Body if an organisation:

- Acts contrary to the aims or interests of ForwardME.
- Fails to attend at least half the meetings in an annual cycle or engage constructively or behaves in a way contrary to the principles of being a member of a collaborative committee.
- Ceases to operate or dissolves.
- Fails to comply with the UK General Data Protection Regulation (UK GDPR), the Data Protection Act 2018 and any other relevant regulations.

The organisation/individual concerned shall have the right to make representations to a person nominated by the admin group before any decision is confirmed. This process would be managed by the admin group.

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## 5. Meetings of the Body

### 5.1 Frequency

The Body shall meet **at least six (6) times per year**. Additional meetings may be called as required by the Chair or by a majority of member organisations.

### 5.2 Notice

- A minimum of **14 days' notice** shall normally be given for all ordinary meetings with agenda and papers at least 7 days before ideally at least 14 days.
- Notice of an AGM needs to be communicated at least 1 month in advance.

- Meetings may be held **virtually or exceptionally hybrid**.

### 5.3 Quorum

A quorum shall consist of at least **one-third of the member organisations**.

### 5.4 Voting

In the rare event of The Body not being able to reach a consensus, the below process should be followed:

- Each member organisation has **one vote**. Decisions shall normally be made by **consensus**; where a vote is required, decisions will be carried by a **simple majority of those present at the meeting**.
- In the event of a tie, the Chair shall have a **casting vote**.
- Individuals do not have a vote, nor do sub groups facilitators.

### 5.5 Record of Meetings

Minutes of each meeting shall be taken and circulated to all members within 7 days.

### 5.6 Annual General Meeting

The Body shall call an Annual General Meeting within 18 months of the previously Annual Meeting. This meeting can be open to non-members and will report on Forward ME's activities over the year, elect Officers for the coming year and shall report on the organisation's financial position and transactions.

For appointing officers at the AGM this shall be done by nominations from individuals or member organisations, seconded by another member organisation, received 7 days in advance. Officers do not have to be from a member organisation. If an election is necessary due to there being more than one nomination for an officer position, this shall be conducted by a simple majority of the member organisations.

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## 6. Governance Structure

### 6.1 The Admin Group

The Admin Group is responsible for the **coordination** of ForwardME between meetings and ensuring progress on agreed actions.

#### Composition:

- Chair

- Deputy Chair(s)
- Secretary (if appointed)
- Treasurer (if appointed)
- Each founding organisation has an invitation to the Admin Group. Founding organisations: ME Association, Action4ME, MEResearchUK, BRAME and MESiG.
- Overall coordinator of sub-groups.
- Others as agreed by the Body.

**Functions:**

- Implement decisions of the Body.
- Make recommendations on policy, priorities, and representation.
- Oversee membership and sub-group activities.
- Act on behalf of the Body between meetings when necessary.

## **6.2 Officers**

**Officers shall be elected by member organisations at the AGM. They shall hold office for one year and be eligible for re-election subsequently for a maximum of 3 years.**

### **Chair**

- Provides leadership and represents ForwardME publicly.
- Chairs meetings and ensures adherence to governance processes, inclusion of all and that the Body is managed competently.
- May take executive decisions, with the Deputy Chair or steering group, between meetings as necessary.

### **Deputy Chair(s)**

- Supports the Chair and acts in their absence.
- May be delegated specific responsibilities by the Steering Group.

### **Treasurer**

- Produces a quartley report on the finances.
- Produces an annual financial report for the Annual Meeting.
- Optional: finds and applies for grants for Forward ME.

### **Secretary or administrator**

- Ensures proper records, minutes, and communication are maintained. Ensures members are fully informed with good notice of meeting arrangements and agendas.

## Sub-Group Coordinator

- Lead and report on specific areas of work (e.g., Research, Health Services, Children and Young People).
  - Must be approved by the Body and form part of the Admin Group.
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## 7. Executive Authority Between Meetings

The **Chair**, **Deputy Chair**, and **Admin Group** have authority to take **executive decisions between full meetings**, provided that such decisions:

- Are consistent with the aims and agreed policies of Forward ME; and
  - Are reported to the next meeting for ratification.
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## 8. Sub-Groups

### 8.1 Establishment

ForwardME may establish sub-groups to focus on specific themes or projects (e.g., Research, Service Improvement, Advocacy).

### 8.2 Membership

- Membership of sub-groups shall be open to representatives of member organisations, individual Forward ME members, and co-opted individuals and wider organisations with relevant expertise or interest.
- Each sub-group shall nominate a **Coordinator/Facilitator** who reports to the Forward ME meeting.

### 8.3 Accountability

Sub-groups operate under delegated authority from the Body and are accountable to it for their actions and recommendations.

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## 9. Finance

- ForwardME shall have the powers to hold funds or assets as agreed by the member body or steering group.
  - Any shared administrative or project costs shall be agreed collectively and managed transparently.
  - If external funding is received, it shall be managed in accordance with UK accounting standards for non-profit associations and used solely for agreed purposes.
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## 10. Conduct and Integrity

All members and representatives are expected to:

- Uphold the values of collaboration, respect, and evidence-based practice.
  - Declare any **conflicts of interest**.
  - Maintain confidentiality.
  - Avoid actions that bring ForwardME or member organisations into disrepute.
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## 11. Amendments

This governance document may be amended by a **two-thirds majority** of votes cast at a duly convened meeting, provided that at least 14 days' notice of the proposed amendment has been given.

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## 12. Dissolution

In the event that ForwardME is dissolved:

- Any remaining funds or assets shall be distributed to member organisations or other non-profit bodies with similar aims, as agreed by the Body.
  - A final report and record shall be circulated to all members.
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## 13. Adoption

This Governance Document was adopted by the members of ForwardME at a duly convened meeting on 5th March 2026, and supersedes any prior governing arrangements.

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### Signed:

Chair: Carolyn Leary Date: 5th March 2026

Deputy Chair: Josh Vince Date: 5th March 2026

Deputy Chair: Julie Upton Date: 5th March 2026

On behalf of the Members of ForwardME

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### Membership of Forward ME March 2026

**Organisations each have maximum 2 seats at main meetings, only one vote per organisation.**

ME Association

ActionforME

BRAME

ME Support in Glamorgan (MESiG)

Tymes Trust

25% Group

Patient Advisory Group for ME Research Collaborative

Hope4ME

ME Local Groups Network UK (MELN UK)

#ThereforME

Physios for ME

#MEAction Scotland

### Individuals

Nina Muirhead - Clinician

Nigel Speight - Clinician

W Weir - Clinician

Chair - Carolyn Leary

Past Chair - Simon Chandler

Admin - Ellie Upton Loach (non-voting)