



The Baby Loss Collective

“Many organisations. One purpose.

One collective voice for every family affected by pregnancy and baby loss”

Terms of Reference

Version: 1.0

Date Adopted: July 2026

Review Date: July 2027

1. Introduction

The Baby Loss Collective is a voluntary alliance of UK charities, organisations, campaigners, advocates and professionals committed to improving the lives of families affected by pregnancy and baby loss.

The Collective has been established to unite the baby loss sector through one strong, collaborative voice that can influence national policy, improve bereavement care and support, raise awareness and advocate for lasting change.

Whilst every member organisation remains independent, the Collective exists because we believe that by working together, we can achieve greater impact than any one organisation can achieve alone.

The Baby Loss Collective is not intended to replace or duplicate the work of existing organisations. Instead, it exists to strengthen the sector by bringing together diverse expertise, experiences and voices, creating a united platform that advocates for meaningful change on behalf of all families affected by pregnancy and baby loss

2. Vision

To be the recognised collaborative voice of the UK baby loss sector, influencing policy, services, legislation and public awareness to improve the experiences of every family affected by pregnancy and baby loss.

3. Purpose

The purpose of the Baby Loss Collective is to:

- Unite organisations across the UK baby loss sector.
- Amplify one collaborative national voice.
- Influence Government, Parliament, NHS organisations and national stakeholders.
- Advocate for improvements in bereavement care, services and family support.
- Raise public awareness of pregnancy and baby loss.
- Ensure the voices and experiences of bereaved families remain central to policy development and service improvement.
- Promote collaborative working across the sector.

4. Objectives

The Collective will:

- Develop and support collaborative national campaigns.
- Represent the baby loss sector in meetings with Government departments, NHS bodies and national organisations.
- Participate in parliamentary groups, including the All-Party Parliamentary Group (APPG) on Baby Loss and other relevant forums.
- Respond collectively to national consultations where appropriate.
- Coordinate representation within national media.
- Raise awareness of issues affecting bereaved families.
- Advocate for improvements in policy, legislation, bereavement care and support.
- Strengthen relationships across the baby loss sector to maximise collective influence.

5. Core Values

The Baby Loss Collective is built upon the following values:

Compassion

Everything we do is centred on improving the experiences of bereaved families.

Collaboration

We believe collaboration is stronger than competition. By working together, we amplify our collective voice and increase our ability to influence change.

Respect

Every member organisation brings valuable knowledge, expertise, lived experience and professional insight. We respect each other's perspectives and recognise the important contribution every member makes to the sector.

Integrity

We communicate honestly, transparently and professionally, always acting in the best interests of bereaved families and the Collective.

Inclusivity

We are committed to representing every form and circumstance of pregnancy and baby loss and to ensuring that all bereaved families feel seen, heard and valued.

Independence

Each member organisation retains its own identity, governance, priorities and areas of expertise whilst contributing to the shared aims of the Collective.

6. Our Collective Principles

The Baby Loss Collective exists to bring together organisations that share a common purpose while recognising and celebrating the diversity of the baby loss sector.

We acknowledge that every member organisation has developed its own expertise, supports different communities, advocates for different aspects of pregnancy and baby loss, and has its own strategic priorities. These differences are not barriers to collaboration; they are one of our greatest strengths.

No single organisation can represent every bereaved family or every experience of pregnancy and baby loss. By working together, we ensure that the voices of all families are represented and that the breadth of knowledge, experience and expertise across the sector is recognised.

The Baby Loss Collective is committed to representing and advocating for **all forms and circumstances of pregnancy and baby loss**, recognising that every family's experience is unique and equally important. This includes, but is not limited to:

- Miscarriage
- Recurrent miscarriage
- Ectopic pregnancy
- Molar pregnancy
- Pregnancy of Unknown Location
- Termination for Medical Reasons (TFMR)
- Stillbirth
- Neonatal death
- Infant death
- Multiple pregnancy loss
- Loss following fertility treatment
- Pregnancy after loss
- Baby loss experienced through any other circumstance or diagnosis

As members of the Collective, we commit to championing one another's work and celebrating the unique contribution each organisation makes. We recognise that strengthening one organisation strengthens the wider sector and ultimately benefits bereaved families.

We will actively support opportunities to:

- Amplify one another's campaigns and initiatives.
- Celebrate achievements and successes across the sector.
- Promote each other's work where appropriate.
- Share opportunities that benefit bereaved families.
- Work collaboratively where our priorities align.
- Speak with one united voice on matters of shared national importance.

The Baby Loss Collective does not seek to replace the identity, expertise or independence of its members. Instead, it provides a collaborative platform through which organisations can stand alongside one another, advocate collectively and influence meaningful change.

Our collective strength comes from our diversity. United by compassion, mutual respect and a shared commitment to bereaved families, we will work together to influence policy, improve services, raise awareness and create lasting change across the United Kingdom.

7. Membership

Membership of the Baby Loss Collective is voluntary and open to charities, organisations, campaign groups, advocates, professionals and individuals who actively support, represent or advocate for bereaved families, or for a specific group affected by pregnancy and baby loss.

Members should demonstrate a commitment to improving the experiences of bereaved families through advocacy, campaigning, service provision, research, policy influence or other recognised forms of support. Together, our members bring diverse expertise, perspectives and experiences that strengthen our collective voice and ensure a broad range of families are represented.

Membership is intended for those working to represent or advocate for bereaved families collectively and is not intended for individual bereaved parents or family members whose involvement relates solely to their own personal experience – See section 11 for 'Supporters of the Baby Loss Collective'.

The Baby Loss Collective is a collaborative alliance, not a networking or marketing forum. Membership is therefore not intended for businesses whose primary purpose is to promote paid products or services.

To be eligible for membership, applicants should:

- Support or advocate for bereaved families collectively, or for a specific community affected by pregnancy and baby loss.
- Demonstrate a commitment to the Collective's vision, purpose and values.
- Agree to uphold these Terms of Reference.
- Work collaboratively and respectfully with other members.
- Act in the best interests of bereaved families and the wider baby loss sector.

Membership applications will be reviewed by the Co-Chairs (and Steering Group, where applicable) to ensure they align with the purpose and values of the Collective.

8. Recognition as a Member

Recognised Members of the Baby Loss Collective are entitled to:

- Be recognised as an official member of the Baby Loss Collective.
- Display the Baby Loss Collective logo on websites and promotional materials whilst membership remains active and in accordance with brand guidance.
- Participate in meetings and discussions.
- Contribute towards campaigns and consultation responses.
- Help shape the priorities and future direction of the Collective.
- Be represented through the Collective's national advocacy and media work.

Recognition as a member demonstrates a commitment to collaborative working for the benefit of bereaved families across the United Kingdom.

9. Membership Fees

Membership is subject to an annual contribution of **£20 per organisation**.

The fee will contribute towards:

- Administration
- Website development and maintenance
- Marketing and communications
- Promotional materials
- Branding
- Events
- Stakeholder engagement
- Other agreed operational costs

The Baby Loss Collective operates on a not-for-profit basis.

All income generated through membership will be used solely to support the operation and development of the Collective.

10. Membership Changes

Membership may be withdrawn by either the member or the Baby Loss Collective by providing **28 days' written notice**.

Upon cessation of membership, permission to use the Baby Loss Collective logo and branding must also cease within 28 days.

The Collective reserves the right to withdraw membership where actions are inconsistent with its purpose, values or reputation.

11. Supporters of the Baby Loss Collective

The Baby Loss Collective recognises the invaluable contribution of bereaved parents, grandparents, siblings, wider family members and members of the public who are passionate about improving care and support following pregnancy and baby loss.

Whilst formal membership is reserved for organisations and individuals who represent or advocate for bereaved families more broadly, the Collective is committed to ensuring that bereaved families remain at the heart of everything we do.

As the Collective develops, a **Supporters of the Baby Loss Collective** network will be established. This will provide an opportunity for bereaved parents, family members, friends and supporters to become part of the wider Collective community.

Supporters will have the opportunity to:

- Receive updates on the work, campaigns and progress of the Collective.
- Engage with awareness campaigns and advocacy initiatives.
- Help amplify the Collective's work through their own networks.
- Be informed of opportunities to contribute to consultations, campaigns, lived experience voices and future projects where appropriate.

The Supporters network will enable individuals to champion the Collective's vision whilst ensuring that formal membership remains focused on organisations and individuals representing the wider baby loss sector.

The experiences and voices of bereaved families will continue to guide and shape the work of the Baby Loss Collective as we strive to improve care, influence policy and create lasting change.

12. Transparency

The Baby Loss Collective is committed to openness and transparency.

The names and logos of recognised members may be published on:

- The Collective website
- Social Media (Instagram, Facebook, TikTok, LinkedIn)
- Marketing materials
- Promotional literature
- Public reports
- Collective communications

This demonstrates the breadth of organisations represented by the Collective and strengthens public confidence in its collaborative approach.

13. Collective Advocacy

The Collective exists to amplify one shared voice whilst respecting the independence of every member.

Collective campaigns, consultation responses, parliamentary engagement and public statements will be developed collaboratively and, wherever possible, through consensus.

Where consensus cannot be achieved, organisations remain free to pursue their own independent positions.

No individual organisation or member may represent themselves as speaking on behalf of the Baby Loss Collective without prior agreement from the Co-Chairs or Steering Group.

14. Representation

The Collective may represent the sector through:

- UK Government meetings
- Parliamentary engagement
- The All-Party Parliamentary Group (APPG) on Baby Loss and Maternity
- NHS England and other UK health bodies
- National consultations
- Media interviews
- Conferences
- Public events
- Stakeholder meetings

Representatives will speak on behalf of agreed Collective positions.

15. Communication

The Collective is intended to be a supportive and respectful environment.

Members are asked to:

- Keep discussions relevant to the aims of the Collective.
- Share information that benefits the wider sector.
- Respect differing opinions.
- Recognise that many members volunteer alongside full-time employment.
- Wherever possible, keep routine discussions to Monday–Friday.
- Respect that members are under no obligation to respond outside their own working hours.

The wellbeing of members is important, and healthy boundaries should always be respected.

Official Communications

Official communications relating to the Baby Loss Collective will be shared via the Collective email address babylosscollective@gmail.com and through the Baby Loss Collective WhatsApp group.

Members are encouraged to ensure their nominated representative regularly monitors these communication channels to remain informed of meetings, campaigns, consultations, events and other Collective business.

The WhatsApp group is intended to facilitate timely communication, collaboration and the sharing of relevant information. Members are asked to use the group respectfully and in accordance with the Collective's communication principles.

16. Governance

The Collective will be led by two Co-Chairs, supported by a Steering Group as required.

The Co-Chairs will:

- Coordinate meetings.
- Facilitate collaborative working.
- Represent the Collective where agreed.
- Oversee administration and membership.
- Ensure members are consulted on significant decisions.
- Organise networking opportunities, events and collaborative spaces that encourage relationship building, the sharing of best practice, knowledge and innovation across the baby loss sector.
- Promote transparency and good governance.

Additional governance roles may be introduced as the Collective develops.

17. Decision Making

The Collective will seek consensus wherever possible. Where unanimous agreement is not possible, differing opinions will be respected.

Collective statements and campaigns will only be issued where there is sufficient agreement amongst members.

18. Meetings

Meetings will normally include:

- A circulated agenda.
- Open discussion.
- Agreed actions.
- Notes or minutes following the meeting.

Additional meetings may be arranged where necessary.

19. Independence

Membership of the Baby Loss Collective does not alter the governance, charitable status or campaigning priorities of individual organisations.

Each organisation remains entirely independent.

The Collective exists to strengthen collaboration rather than replace individual organisational identities.

20. Founding Sponsorship

The Baby Loss Collective has been established with generous founding sponsorship from **CuddleCot**.

This sponsorship has supported the launch and initial development of the Collective.

The Baby Loss Collective remains an independent alliance.

Founding sponsorship does not provide decision-making authority, influence over policy positions or preferential representation. All decisions are made collectively and in the interests of the baby loss sector and bereaved families.

21. Review

These Terms of Reference will be reviewed annually and updated as the Collective develops.

Our Collective Commitment

The Baby Loss Collective exists because meaningful change is achieved through partnership.

We recognise that every organisation, campaigner, advocate and professional brings unique knowledge, expertise and experience. Together, we are stronger than any one organisation alone.

By working collaboratively, we will amplify the voice of the baby loss sector, influence decision-makers, support one another and strive to improve the experiences of every family affected by pregnancy and baby loss.

United by compassion, guided by integrity and driven by a shared commitment to change, we stand together to ensure that bereaved families are heard, represented and that their babies are never forgotten.