

**Terms of Reference for the**

**Advisory Council**

**Purpose**

1. The Advisory Council brings together representatives from across the children’s palliative care sector, including those with lived experience, to share their expertise and insights. Together, they inform and advise the work of Together for Short Lives on the key issues and opportunities shaping children's palliative care.
2. The representatives on the Advisory Council also have a responsibility to communicate with their related stakeholders in the children's palliative care sector both to understand their views and issues and to share the outcomes of the Advisory Council meetings and the work of Together for Short Lives.
3. A core principle of the Advisory Council is that the lived experience of families, carers, and children and young people is at the heart of its work. This perspective will shape agendas, discussions, and recommendations, ensuring the voice of those most directly affected by children’s palliative care informs all strategic advice.

**Membership**

1. The Advisory Council will consist of up to 25 members, made up as follows:

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| **Group** | **Max. Number of representatives & current numbers in brackets** | **Notes** |
| Families, carers and young people | 5 (3) | Aim to get broad representation including parents, young people, bereaved parents etc. At least 2 young people, so they can support one another. |
| Statutory sector  | 6 (2) | Representatives from:* Specialist doctors
* Nursing
* Social care
* Commissioning
* Others as deemed appropriate
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| Children’s hospices | 4 (3) | Can include CEOs, Chairs, Directors of Care, Fundraising, Finance, Communications, Community care and volunteers |
| Non-hospice charities | 3 (0) | Condition specific and charities operating in related areas of healthcare and support |
| National Partners | 2 (1) | e.g. Hospice UK, Council for Disabled Children, Disabled Children’s Partnership, APPM etc |
| Research & policy | 2 (1) |  |
| Together for Short Lives  | 2 (2) | Chair of the Board of Trustees and one other trustee |

1. The Advisory Council is committed to being inclusive and reflective of the full breadth of the children’s palliative care community. Membership will include people with lived experience, and individuals at various levels of seniority and roles within organisations to ensure diverse voices are heard, including those working on the front line, in voluntary roles, or with grassroots perspectives.
2. The appointment of members of the Advisory Council will be overseen by the Appointments Committee (and/or Chair) of Together for Short Lives.
3. For most categories of members, members of the Advisory Council will be appointed through a process that will invite expressions of interest from members, stating the particular skills & backgrounds required. For some categories, particular methods of appointment will be agreed to get the best engagement with that group.
4. The appointment process will be designed to be inclusive and accessible, using clear, jargon-free language and flexible formats to encourage participation from a wide range of applicants, including those who may not traditionally see themselves as candidates for governance or advisory roles.
5. The Advisory Council will include members from each of the four nations within the UK. Where this is not achieved through the appointments, the Chair of the Advisory Council will make additional appointments to ensure the four nations are represented.
6. Each representative will serve for a term of three years up to a maximum of two consecutive terms.
7. The Chief Executive of Together for Short Lives, and other relevant staff, will have the right to attend any meeting, but will not be formal members of the Council.
8. The Council may co-opt other members and may invite other individuals or representatives to attend for all or part of any meeting when needed.
9. Together for Short Lives will meet with each representative (and additional members, practitioners and representatives) outside of the meetings on an annual basis
10. At present, the Chair of the Advisory Council is the Chair of the Board of Trustees of Together for Short Lives; however, alternative approaches to this arrangement will be considered at the appropriate time to ensure strong engagement, broad representation, and a shared sense of ownership across the sector
11. A Vice-Chair of the Advisory Council will be appointed within the first 6 months to work alongside the Chair.

**Authority**

1. The function of the Advisory Council is to be representative of the children's palliative care sector and to advise the Board of Together for Short Lives.
2. The Advisory Council is authorised by the Board to request information from the Chief Executive of Together for Short Lives as required to perform its duties, up to this not being unduly onerous.
3. The Board of Trustees may alter these terms of reference, or disband the Advisory Council, if it deems it is in the best interests of the charity to do so.
4. The Advisory Council and the Board will carry out a review of these arrangements on an annual basis.

**Duties**

The Advisory Council will use their respective knowledge and experience of children's palliative care to:

1. Advise the Board of Together for Short Lives on pertinent and relevant sector and subject matters which will guide Together for Short Lives on its direction and priorities.
2. Collaborate with Together for Short Lives when needed either on an individual basis or through any groups/committees established by the Board to advise and develop specific areas of Together for Short Lives’ work.
3. Bring matters of interest or concern from particular groups to the attention of the Board.
4. Undertake such activities as may be requested or delegated to the Advisory Council by the Board within the purpose defined in para 1-3.
5. The Advisory Council Chair will report formally to the Board on its proceedings after each meeting on all matters within its duties and responsibilities.
6. The Advisory Council Chair will update the Advisory Council on relevant Board meeting discussions.
7. The Advisory Council will make recommendations to the Board on areas within its remit, as it deems appropriate.
8. The Advisory Council will, at least once every two years, review its own performance and terms of reference to ensure it is operating at maximum effectiveness and share its views with the Board.

**Frequency and Conduct of Meetings**

1. The Advisory Council will meet three times a year, or more regularly as its Chair may decide in order to conduct its business.
2. Except as otherwise prescribed in these terms of reference, the provisions of Together for Short Lives’ Articles of Association applicable to trustee meetings will apply to meetings of this Advisory Council.
3. The quorum necessary for the transaction of business will be one-third of the representatives defined in paragraph 4. A duly convened meeting of the Advisory Council at which a quorum is present will be able to carry out its responsibilities the Advisory Council.
4. Meetings of the Advisory Council will be called, by staff of Together for Short Lives, at the request of the Chair or any three of its members.
5. Unless otherwise agreed, notice of each meeting confirming the venue, time and date together with an agenda of items to be discussed, will be forwarded to each member of the Advisory Council and any other person required to attend, at least 5 working days before the date of the meeting.
6. If a member is unable to attend a meeting, where appropriate they may send a “deputy” so that their organisation is represented at the meeting.
7. Staff of Together for Short Lives will minute the proceedings and recommendations of all Advisory Council meetings, including the names of those present and in attendance.
8. Minutes of Advisory Council meetings will be circulated promptly to all members of the Advisory Council and to all members of the Board by staff of Together for Short Lives.
9. Draft minutes will be circulated, via Together for Short Lives, to all members of Together for Short Lives once agreed by the chair.
10. Expenses incurred by members to attend meetings of the Advisory Council will be reimbursed by Together for Short Lives.
11. The Advisory Council will ensure that meeting agendas and formats are co-designed where appropriate with members who have lived experience, and structured to be accessible, inclusive, and sensitive to their needs and time commitments.
12. The Advisory Council or the Board of Trustees may remove a member by majority vote after consulting both the individual and, where relevant, the organisation they represent.
13. Members may resign at any time by notifying the Chair. A member who misses three consecutive meetings without good reason may be removed by a majority vote of the Advisory Council.