

Lewisham Carers Forum: Draft Terms of Reference

What is the Carers Forum ('The Forum')?

Lewisham Council believes that carers should be **visible, valued and supported**. The Council wants support for unpaid carers to be the best it can be. It has set up the Carers Forum so that carers can exercise their rights, express their views and influence how the support they need should be provided; to help improve the quality of support and services as well as to get news about issues that affect them.

Who is considered a Carer?

- A 'carer' is anyone, including children and adults, who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is **unpaid**¹.
- As agreed with carers, for clarity, in this Forum we will also refer to people who care for another, or have been a carer, as an 'unpaid carer'.

Purpose of the Carers Forum

- To amplify the collective voice of unpaid carers on matters that affect them;
- To inform members of the Forum about Carers Rights and promote better general awareness;
- To promote the positive contribution that carers make to our local community and the economic benefits of this;
- To engage and collaborate with other agencies to encourage a culture of positive attitudes and language about caring and the role of carers as partners in care, support and treatment;
- To create a collaborative and inclusive space, which embraces our diverse community, to discuss unpaid carers challenges, share experiences, and propose solutions.

The Carers Forum and Lewisham Council will work in partnership, in a way of working described as 'coproduction'²; *this, according to statutory guidance on Care Act 2014, can be 'when an individual influences the support and services received, or when groups of people get together to influence the way that services are designed, commissioned and delivered'*.

¹ <https://www.england.nhs.uk/commissioning/comm-carers/carers/>

² <https://www.scie.org.uk/co-production/what-how/#whatis>

Governance and the steering group

- This Forum will be led by a steering group elected by the members of the Carers Forum;
- The steering group will elect a Chair and Deputy (or Co-Chairs) to lead both the steering group and the Carers Forum meetings. The Chair must be an unpaid carer currently or have been one in the past;
- The steering group will take responsibility for ensuring that these Terms of Reference are applied with the support of resources including council officer time, meeting space, access to online technology and budget as designated by Lewisham Council. The group will be accountable for ensuring the Carers Forum is run in accordance with the Terms of Reference.

Objectives:

- Ensure the Carers Forum:
 - Enables unpaid carers to be listened to and for a record of their views to be shared to influence decision-making;
 - Encourages unpaid carers to contribute to consultation on all carer related future Lewisham Council procurement as well as to evaluation of current services, with a record of views published;
 - Facilitates all unpaid carers to feel they have a stronger voice and influence over decisions that affect them, taking account of equality and diversity issues, communication needs and preferences, unpaid carers who are also in paid work or full time education and those who may feel disenfranchised, marginalised and forgotten;
 - Enables unpaid carers who wish to be involved to be able to do so in a way that works for them to include:
 - Improved sharing of information for and with unpaid carers;
 - Direct communication with unpaid carers about the work of this group;
 - Attendees at meetings, whether in the room or online, to be given time to speak openly but with respect;
 - Attention given to things that can ensure the Forum is accessible and responsive to the varied circumstances of carers such as those in paid employment or full-time education – e.g., timing of or recording of meetings
- Develop a forward plan with a series of action statements and outcome measures;
- Work in partnership with Lewisham Council and external partners towards embedding co-production throughout Lewisham;
- Produce an annual report to the Health & Wellbeing Board.

Values and Behaviour – *start with these at every meeting and send to invited guests*

The Carers Forum operates based on the following core values:

- **Empathy:** Members and partners attending actively listen to each other, showing understanding and compassion.
- **Dignity and Respect:** All participants treat one another with courtesy and honour diverse perspectives.
- **Equality, Diversity, and Inclusivity:** The forum promotes equality, diversity and inclusion and welcomes Unpaid Carers from all backgrounds, regardless of age, disability, ethnicity, gender, sexual orientation or socioeconomic status.
- **Collaboration:** Members and partners work together to find innovative solutions and support one another – including through peer support.
- **Confidentiality:** Matters of a personal nature shared within the forum remain confidential, respecting privacy.
- **Positive engagement:** Expected behaviour includes active listening, constructive feedback, and a commitment to fostering a supportive community.

Membership:

The Forum is open to:

- Carers as defined by the Care Act, ‘an adult who provides or intends to provide care for another adult (an “adult needing care”)’;
- People who have provided unpaid care and support in the past and have an interest;
- For clarity, we use ‘unpaid carer’ to describe carers, or those who have provided care, to distinguish them from paid staff. We recognise that some unpaid carers may also be in paid work in the health and care sector;
- Young carers – under 18 - are included and welcome to join the Carers Forum;
- Representatives from partner bodies such as Healthcare agencies, other organisations and groups may join when invited by the Forum.

Meetings and Communication:

- The Forum convenes monthly for 6 months and then will be reviewed; the activities and running of the Forum will then be reviewed annually.
- Agendas are prepared in advance, allowing input from all members;
- Communication channels include an online platform, email, and social media. Some paper-based information will also be produced and sent on request for those without access to digital platforms. In partnership with the Council, the Forum will consider options for people with specific communication needs.

Topics and Activities:

- Topics and activities are driven by the members of the Forum.

Glossary³

- **Accountability:** When a person or organisation is responsible for ensuring that things happen, and is expected to explain what happened and why.
- **Active listening:** A way of listening that enables you to be fully heard, especially if you have dementia or difficulties with communication. Someone who is actively listening to you will be making eye contact, not interrupting, giving you their full attention, not doing other things, and checking with you that they understand what you are saying.
- **Adult social care:** Care and support for adults who need extra help to manage their lives and be independent - including older people, people with a disability or long-term illness, people with mental health problems, and carers. Adult social care includes assessment of your needs, provision of services or allocation of funds to enable you to purchase your own care and support. It includes residential care, home care, personal assistants, day services, the provision of aids and adaptations and personal budgets.
- **Advocacy:** Help to enable you to get the care and support you need that is independent of your local council. An advocate can help you express your needs and wishes, and weigh up and take decisions about the options available to you. They can help you find services, make sure correct procedures are followed and challenge decisions made by councils or other organisations.
- **Carer's Allowance:** A weekly payment from the Government if you provide support to a partner, family member, friend or neighbour, who could not manage without your help. You don't have to be related to the person or live with them to be able to claim Carer's Allowance. Whether you can claim it depends on how many hours a week you provide care for, what benefits the person you care for receives, and how much you earn (but not how much money you have in savings).
- **Carer's assessment:** If you are an unpaid carer for a family member or friend, you have the right to discuss with your local council what your own needs are, separate to the needs of the person you care for. You can discuss anything that you think would help you with your own health or with managing other aspects of your life. The council uses this information to decide what help it can offer you.
- **Commissioning:** The process of planning services for a group of people who live in a particular area. It does not always mean paying for services, but making sure that the services people need are available in that area.
- **Co-production:** When you as an individual are involved as an equal partner in designing the support and services you receive. Co-production recognises that people who use social care services (and their families) have knowledge and

³ TLAP Care and Support Jargon Buster,
<https://www.thinklocalactpersonal.org.uk/Browse/Informationandadvice/CareandSupportJargonBuster/>

experience that can be used to help make services better, not only for themselves but for other people who need social care.

- Dignity: Being worthy of respect as a human being and being treated as if you matter. You should be treated with dignity by everyone involved in your care and support. If dignity is not part of the care and support you receive, you may feel uncomfortable, embarrassed and unable to make decisions for yourself. Dignity applies equally to everyone, regardless of whether they have capacity.
- Direct payments: Money that is paid to you (or someone acting on your behalf) on a regular basis by your local council so you can arrange your own support, instead of receiving social care services arranged by the council. Direct payments are available to people who have been assessed as being eligible for council-funded social care. They are not yet available for residential care. This is one type of personal budget.