

Cancer Alliances' Carers Focus Group Report

27 November 2025

Executive Summary

- **Communication:** Often excellent during treatment but poor at discharge.
- **Emotional support:** Rarely offered, carers often had to seek help themselves. When offered, people were unsure if helpful. Support for wider family also lacking or not appropriate.
- **Preparation for life beyond cancer:** Many felt unprepared and unsupported.
- **Complex caring roles:** Many carers were supporting multiple family members.
- **Advocacy:** Many carers are disadvantaged through a lack of self-advocacy experience to navigate the complexity of health services.
- **Continuity and coordination:** Gaps in care pathways caused stress and risk.
- **Recognition of carers:** Simple gestures like asking 'Are you OK?' mattered greatly.

Background

Wessex Cancer Alliance and South East London Cancer Alliance are aware there is limited insight into the experience of caregivers/carers who are supporting people affected by cancer. There are pockets of good practice and examples of great services for carers, however these are not uniformly available.

Caregivers often do not identify as carers; they see it as something you do for loved ones. The role is, however, intense and challenging, often underestimated by others so we wanted to specifically explore what we can do to support people better.

"It's really complicated... people don't see themselves as a caregiver."

"We just get on with it and try not to think about ourselves too much."

Our starting point was to hold a 90-minute online focus group with 8 caregivers of people affected by cancer from across the country (some of those attending also had a cancer diagnosis themselves). This took place on 27 November 2025. The purpose was to identify what worked well, what did not, and what would make the biggest difference to caregivers. Discussions were structured around these key points.

Note, the terms 'caregivers' and 'carers' are used interchangeably through this report referring to people who provide unpaid support to someone with cancer, usually a close family member or friend.

Findings

What worked well?

Key points:

- Communication and care during treatment was often excellent, with multidisciplinary teams working together.
- Personalised care and respect for family roles made carers feel included.
- Charities, faith-based organisations and hospices provided valuable practical and emotional support.

"Communication was brilliant – we felt listened to and part of it all."

"Hospice care was excellent; they adapted the house and supported us both."

"I envied members of my family with cancer that had faith as the Church provided the support for them that I would've expected from the GP."

What could be improved?

Key points:

- Discharge processes were chaotic, leaving carers unprepared and unsupported.
- Continuity of care broke down after hospital treatment ended.
- Emotional support was rarely offered; carers had to seek it themselves and it was often lacking for wider family members. The emotional burden and fear of recurrence remain long after treatment ends.
- Carers often juggle multiple roles, including caring for elderly parents or children and looking after the wider family.
- There is a significant financial burden of caring. There is low awareness of support on offer, and is often complicated and slow to respond.

"Discharge was a nightmare – no explanation, no support, just a huge bag of meds. I had to Google how to crush tablets because no one told me what to do."

"You've got a middle-aged woman trying to talk to a teenage boy about losing his mum. He'd rather talk to his mates or a bloke or a computer game."

"I was caring for my mum and my daughter with cancer at the same time. The combined, and sometimes competing demands were hideous."

"The shadow of cancer never leaves; triggers bring it all back daily."

What would have made the biggest difference to you in your caregiving role?

Key points:

- Better preparation for life beyond cancer, including practical guidance.
- Recognition of carers through small gestures (e.g. asking 'Are you OK?').
- Accessible emotional and psychological support tailored to family needs.

"Just someone asking, 'Are you OK?' would have meant a lot."

"Preparation for living beyond cancer – we fell off a cliff."

Suggestions from focus group participants

- Develop and pilot a national cancer carers survey to capture experiences and needs.
- Provide emotional and psychological support options for carers based on individual needs.
- Improve discharge and continuity to Community/GP care with carer involvement.
- Create practical guides, including offers of financial support, for carers on living with and beyond cancer.
- Introduce carer recognition initiatives as appropriate (e.g. [national care lanyards/cards](#), free refreshments).
- Ensure equitable access for carers who cannot advocate for themselves or are unaware of how the NHS works.
- Ensuring that carers are aware of support services already available to them.

Next steps

Our next steps will be to:

- Share this report with those who came to the focus group for their comments and reflections.
- Share with NHS England experience of care leads and other Cancer Alliance Patient Engagement and Experience leads.
- Identify and agree priority area/s for improvement with carers to support the development of an action plan.
- Consider how to involve carers from a range of different backgrounds to ensure this work is inclusive of a wide range of people and communities.

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