

Summary of CLIO Research Findings

More people than ever are living with and beyond cancer, but many experience loneliness during and after their treatment. Loneliness can occur even when people are surrounded by family and friends, and we still know relatively little about why it happens or what helps. The CLIO study explored the experiences of 18 adults living in East Kent with firsthand experience of cancer.

Interviews revealed that cancer for many, was life-changing and disrupted their sense of who they were and how they related to others. This meant they felt that they could not return to who they had mentally and physically been before diagnosis. This also affected the sense of the future that they had anticipated for themselves.

They described how relationships could become strained, because they couldn't discuss their experiences with people close to them, or because others didn't know what to say, worried they would cause upset, or said the wrong thing. This meant that for some of the people interviewed, there was a preference to spend time alone even though they felt lonely.

The study also showed that some factors made loneliness more likely to exist. For example, having or expecting a poor cancer outcome, being lonely prior to having cancer, having additional significant life stressors before or during the cancer experience, and not having the support of a life partner during cancer.

Meeting and talking with others who had experienced cancer was often described as very important because it provided understanding, information and a sense of connection. However, some people found it difficult to connect with others in similar situations, particularly if they had a rare cancer type or unique experiences. For others, cancer-related health problems or disabilities made it harder to take part in social activities. These challenges could also increase feelings of loneliness.

The CLIO study explored what people do themselves to manage loneliness. Participants described using strategies that *help in the moment* to alleviate their feelings such as:

- Deliberately distracting themselves
- Being in nature often, with pets or friends
- Being creative
- Keeping mentally and physically occupied

Some found that *repeated strategies over time* helped them, such as:

- Seeking out information that could help make sense of the experience
- Actively acknowledging their own experience
- Adjusting their way of thinking about the experience
- Processing thoughts and emotions through creative opportunities
- Actively nurturing important relationships
- Connecting with other people affected by cancer
- Volunteering and helping others

Many people used several of these approaches at the same time. Interestingly, some participants who had never experienced loneliness also reported using these strategies, which suggests that these strategies may help people adapt to the challenges of cancer. However, this area requires more research in the future.

Overall, the findings of the CLIO study suggest that cancer-related loneliness is shaped by a combination of personal, social and practical factors. The study examined what people do to manage their loneliness but revealed that a wide range of external factors may influence how easily people are able to use the strategies, for example the availability and affordability of services.

The study recommends that support for people living with cancer should go beyond simply increasing social contact and should be directed at helping individuals make sense of their experiences, maintain meaningful relationships and, access support that is appropriate to their circumstances. Future research will use these findings to help develop interventions aimed at reducing loneliness among people affected by cancer.

Stakeholders, people with cancer, carers and relevant interested parties will be invited to a focus group in late 2026, to discuss these findings and plan for the next steps. It is anticipated the next steps might include an application for funding to aid the development of codesigned interventions for loneliness that can be tested.

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