

# More support needed for cancer patients and carers impacted by COVID-19

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The effects of the coronavirus pandemic on people living with cancer need to be acknowledged and better understood to address long-term care challenges and help improve quality of life for patients, their family members and friends, or carers, a new report concludes.

Research undertaken as part of ENABLE—an ongoing qualitative study led by the Macmillan Survivorship Research Group at the University of Southampton, with The Christie NHS Foundation Trust and the University of Plymouth, funded by Macmillan Cancer Support—found [cancer](#) patients and their carers have experienced many changes since the COVID-19 outbreak which have negatively affected normality, their independence and the control of their lives.

[The report](#) is based on qualitative interviews (between March and May 2020) with 21 people living with cancer that is treatable but not curable, following UK shielding guidance (12 patients and 9 carers).

Participants expressed that since the pandemic began:

- Levels of anxiety and uncertainty had increased;
- Restrictions on seeing loved-ones had a significant impact on the wellbeing of both patients and carers. Although technology helped, not all had access;
- They had lost opportunities to do the things that were important to them in the limited time they had left to live;
- It was no longer possible to attend social activities which

normally helped maintain a sense of purpose;

- Shielding guidance was confusing, particularly in relation to patients' contact with carers;
- Routines and tasks at home increased in importance, providing 'coping strategies';
- A higher burden of care was sometimes placed on carers, who also had less access to support and respite;
- Health care teams continued to support them well, such as with phone consultations, but there was concern about the longer-term impact of changes to aspects of their treatment.

The report authors suggest that:

- Conversations are held within cancer professions and with the public to acknowledge the impact of the pandemic and develop a response;
- Health professionals consider ways to include carers in consultations and that their own health and wellbeing is taken into account;
- Health professionals are given time to prepare for difficult conversations about COVID-19 and its impact on treatment;
- The experience of those shielding is fed into any new pandemic guidance;
- 'Safe areas' are created where patients and carers can meet face-to-face with clinical and support staff—particularly for those people with no access to online resources.

Dr. Lynn Calman, ENABLE project lead and Deputy Director of the Macmillan Survivorship Research Group at the University of Southampton commented: "Our study gives us a snapshot and rich insight into the sudden impact the COVID-19 pandemic has had on the lives of [cancer patients](#) and their carers. It is crucial that [health professionals](#) are able to recognise the effect the outbreak is having and

develop strategies to help people facing significant health challenges to improve the quality of their lives."

Dr. Rosie Loftus, Chief Medical Officer for Macmillan Cancer Support said: "At Macmillan we know that many people living with treatable but not curable cancer already face significant uncertainty and anxiety, and it is clear from this research that the COVID-19 pandemic has exacerbated the challenges faced by this group. It is heartening to see that participants in this study still felt well supported by the healthcare professionals involved in their cancer care, but consideration must be given to supporting cancer professionals to prepare for challenging conversations about long term impacts of treatment changes triggered by the pandemic.

"There is much to learn from the experiences of the study participants around shielding and any planning around the future reintroduction of shielding should take these experiences into account to improve the clarity of information and the quality of support provided to those asked to shield.

"Myself and colleagues from across Macmillan will be drawing on the findings from this report to help ensure that we are doing everything we can, and influencing others to do everything they can, to support people living with cancer during this challenging time. It is critical that cancer does not become the forgotten 'C' in the crisis."

[The ENABLE study](#), of which this report reflects a subset of interviews, has the overall aim of understanding and characterising the value and role of supported self-management for patients living with cancer that is treatable but not curable and their carers. Longitudinal interviews (three over a year) explore how perspectives, strategies and needs change over time in relation to self-management and unpredictable illness trajectories. In total, 30 patients and 22 carers are continuing to

participate in the wider study.

Provided by University of Southampton

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