



Rising to the challenge of COVID-19 while living with cancer

“Treatments have been delayed and on many occasions stopped. People with cancer have been dying during this period, or finding that their disease has progressed. It’s been a heightened time of distress and anxiety. Our centre staff have said they’ve never dealt with such levels of fear and feelings of anger.”

Dame Laura Lee DBE, Chief Executive, Maggie’s – speaking to The Today Programme, BBC Radio 4, August 2020



“One of the girls in my bereavement group said we felt like we were just coming out of isolation, only to be forced back into a lockdown because of coronavirus. Maggie’s has been a lifesaver during coronavirus, I couldn’t have coped without them.”

Claire, Edinburgh



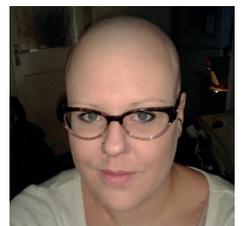
“Right now, Covid absolutely terrifies me. I’ve been lucky to not have had any of my treatments stopped, but the worrying thing about Covid is that that very vital scientific research into new cancer treatments has been put on hold for the time being, however, cancer is not going to go away. Recent figures have shown that 400 people die of cancer every day and even if we get a vaccine for coronavirus, or the next son-of-coronavirus, cancer will still be here; it will affect one in two people, so research into new treatment is still necessary.

Lisa, Edinburgh



“Having to come off my treatment due to coronavirus was so difficult, cancer doesn’t stop because of coronavirus. It’s a terrifying situation but less terrifying when you’ve got support networks like Maggie’s.”

Shelley, 35, Newcastle



ABOUT MAGGIE'S

In 2020 Maggie’s practical, emotional and psychological support is needed more than ever.

We have been supporting people with cancer and their loved ones for 25 years, through a network of centres across the UK and internationally; and our evidence-based programme has been proven to improve physical and emotional wellbeing, cementing Maggie’s position as a world leader in cancer care.

But we have never seen such extreme distress as we have seen during the pandemic.

When lockdown began in March 2020, people were told to protect the NHS and stay at home to save lives. The public took this message seriously, and as a result, fewer people went to their GP with potential cancer symptoms, causing a decline of up to 80% in urgent cancer referrals.

The result of this WILL be an increase in the number of avoidable deaths. It is now predicted that there could be as many as an additional 18,000 cancer deaths in the UK in the coming year.

In the first month of lockdown, Maggie’s provided support 11,000 times over the phone, online or by e-mail. We were inundated with calls from people with cancer realising they might die early with Covid-19; who couldn’t say a proper goodbye to their loved ones, knowing their last days may be spent stuck at home or in hospital, alone; who were devastated that clinical trials stopped to prioritise Covid-19 studies, and research was halted.

It was clear those coming to us for support were experiencing unprecedented levels of trauma.

We quickly moved our high-quality individual support onto the phone, email, Facetime, Skype and Zoom and had provided support over 74,000 times by the end of August.

For more than a third of people with cancer who are in work, Covid-19 has left them struggling to pay bills; and 60,000 people living with cancer have been left with no income at all during the crisis; by the end of August, our Benefits Advisors had provided over 16,000 sessions

to people with cancer in financial crisis, helping them claim benefits and emergency grants, explaining what furloughing means for their income and fast tracking our visitors' applications to circumnavigate the huge volume of new enquiries creating a backlog in the benefits system.

People already diagnosed with cancer tell us we have been a lifeline during lockdown when many other medical and familial support networks were unavailable.

“Life during lockdown, without Maggie’s? I couldn’t have coped.”

Maggie’s centre visitor

We have also been there for our colleagues in the NHS, supporting 10,000 visits from NHS staff, providing psychological support, mindfulness, relaxation and a place to escape the stressful hospital environment, relax, or make difficult phone calls.

As restrictions eased in the summer our centres welcomed people back in for face-to-face sessions with Cancer Support Specialists and Psychologists. We were incredibly careful to ensure the safety of our centres, but we also knew how important it was for people to once more be able to experience the warmth of our centres, designed to foster a sense of wellbeing, and the heightened quality of face-to-face support.

Now though with increased restrictions back in place across the UK, there are 1000’s of people struggling to cope with cancer and the long-term impacts of the coronavirus such as fear, trauma and heightened anxiety

borne out of lockdown, shielding, treatment delays and potentially worse outcomes.

We expect that COVID-19 will impact cancer outcomes for years to come as the huge physical, psychological and emotional consequences of delayed diagnosis and missed treatments become realised. In the last six months we have heard from people with cancer experiencing unprecedented levels of trauma, fear and stress because of the devastating impact of the coronavirus.

- 1 in 3 treatments delayed¹
- GP cancer referrals down by as much as 80%²
- As many as 18,000 additional deaths from cancer in the coming year²
- Increased demand for our support now and over the coming years

People with cancer are scared and angry; many feel they have become the collateral damage of the pandemic – cancer has become ‘The Forgotten C’.

We know that levels of trauma and psychological stress amongst those living with cancer will only increase as people face worsened outcomes, delayed diagnosis and severely impacted mental health.

The next 12 months will be a terrible time for people with cancer as the NHS plays catch up from 2020. We know this is going to bring a lot of anguish to people living with cancer and know that never before has the need for psychological support been greater. We also believe that, based as we are on hospital grounds, we are in the best possible position to provide such in-depth, crucial support at this time.

OUR SPOKESPEOPLE

We would be happy to offer two spokespeople to speak to the All Party Group:

Dame Laura Lee, Maggie’s Chief Executive

With a background as an oncology nurse, Dame Laura was instrumental in helping turn Maggie Keswick Jenck’s vision for a different type of cancer care into a reality. As Chief Executive she has overseen the growth of the organisation from the original centre in the grounds of the Western General Hospital in Edinburgh, to the 23 now to be found in the grounds of NHS hospitals across Great Britain. As well as developing our evidence based programme of support to meet the practical, emotional and psychological needs of people living with cancer.

Storytellers

We have many storytellers willing to speak about their experiences of living with cancer during the pandemic, including those who have been directly impacted by treatment delays, worsened outcomes and extreme distress.

“Because of coronavirus, my children couldn’t visit me on the ward. I was overwhelmed when I was told I could see my family on Mother’s Day at Maggie’s. It’s a memory we’ll never forget. Maggie’s have gone above and beyond and I don’t know where we’d be without them.”

Jamie, 28, Newcastle



“The biggest thing about being in isolation is the fact that there’s no human contact. I just want somebody to sit down and hold my hand or give me a hug. It can be so difficult. Although seeing somebody out of the window can be helpful, it can also exacerbate the feeling of loneliness and be heart breaking.”

Malita, Dundee



¹ 1 in 3 people with cancer surveyed by CRUK in their Cancer Patient Experience Survey July 2020 said that their treatment had been impacted.

² University College London Institute of Health Informatics and DATA-CAN: The Health Data Research Hub for Cancer, as published in HDRUK, Aug 2020. Lead author Dr Alvina Lai.