

"Hoping for the best and preparing for the worst" - Understanding the needs of people living with treatable but not curable cancer and developing solutions for choice and support for people

Dany Bell

Macmillan Cancer Support, UK

In England at least 17,000 people who have survived for two years or more after being diagnosed with stage 4 cancer. The figures are based on people in England who were diagnosed with one of ten common types of cancer between 2012 and 2013, and still alive at the end of 2015. This is the first time that data showing the number of people in England living several years after being diagnosed with stage 4 cancer has been available. These figures highlight the changing nature of cancer. There are now thousands of people who have been diagnosed with the most advanced stage of cancer as new and improved treatment means they are able to live for several years. Patients who previously had more limited options now see their cancer become more 'treatable' and manageable, like other chronic illnesses. However, these patients often face a complex range of issues, including living with uncertainty over how their cancer will progress, and having to make difficult decisions about potentially life-extending treatment that effects their quality of life. Coping with the physical symptoms of cancer, having multiple hospital appointments, scans and treatment options to contend with, there's also the emotional and psychological impact of having an uncertain future. Carol, 55, from London was diagnosed with stage 4 breast cancer in 2015. She says: "Since my diagnosis, I have learnt how to adjust and come to terms with my new self. I am still Carol - a mother, wife, sister, friend and colleague. I am learning to live with a progressive disease and uncertainty every day. Research highlighted patient views around language often used and

how it disempowers them. Research to identify this emerging cohort of patients as well as solutions as to how to provide greater choice and support in the face of great uncertainty. This includes:

- Data from England on the numbers of people living with treatable but not curable cancer
- Insight from Macmillan Cancer Support's strategic work in this field
- Findings from a UK ethnographic study commissioned by Macmillan Cancer Support, looking at the experiences of professionals and people living with incurable cancer and the missed opportunities for shared decision making and advance care planning. This will include some case study videos
- Debate on the language and how to describe this emerging field alongside existing terminologies used such as supportive, palliative and terminal care

Speaker Biography

Dany Bell is Specialist Advisor for Treatment and Recovery at Macmillan Cancer Support. She is a Registered General Nurse with 31 years' experience in the NHS. Has a Diploma in Palliative Care and Master of Science Degree in Pain Management. During her career she has clinically managed a surgical oncology ward, hospice ward, has experience as a clinical nurse specialist in specialist palliative care as well as being lead clinical nurse for a hospital specialist palliative care team. Has undertaken senior management roles in the NHS including lead cancer nurse and cancer manager as a joint role; as well as a head of operations role for an acute trust. She has been employed by Macmillan since April 2014. In her current role she advises Macmillan on strategic direction and provides insight and expertise across treatment and recovery thematic areas.

e: DaBell@macmillan.org.uk