

### **How to raise awareness of the signs and symptoms of cancer**

It is vital that people with a palliative diagnosis and their families be made aware of the signs and symptoms of dying of or with cancer, as well as the signs and symptoms that can lead to a diagnosis, and this 10 year plan must account for this. The negative impact on the person dying and their loved ones if the signs of dying are not sufficiently communicated can be huge, particularly if they are dying at home. In summer 2020, Maureen's parents died within four weeks of each other, in her sister's living room. Maureen and her siblings were unprepared for the realities of caring for their parents at end of life. They were not even warned that their Mum was dying when she was discharged from hospital, only discovering this when Maureen read that she had 'days to one week to live' in her medical notes. Maureen and her siblings were passionate carers of their parents in their last days and weeks but were left with insufficient guidance, and inconsistent and often poor care from the NHS and carers who were meant to support them.

In order to prevent what happened to Maureen's family and many others being repeated, the Government must ensure that the generalist health and care workforce are trained in basic palliative and end of life care in order to spot the signs of dying and communicate this appropriately to patients and the people important to them. This workforce delivers a significant proportion of palliative and end of life care and has taken on a lot of this responsibility over the course of the pandemic.

One of the most effective methods of raising awareness of the signs and symptoms of cancer and of dying is working with advocates with lived experience. There are many ways to achieve this, through education, training and storytelling, which enables a more person-centred approach to understanding the issues and challenges associated with cancer diagnosis, treatment and care. Encouraging people who have lost loved ones to share their story can also help them to process their grief and tackle the taboo around talking about death and dying.

There also needs to be widespread understanding of the signs and symptoms of cancer in various groups and how to spot them. This includes, for example, awareness of the differences in cancer screening procedures after gender reassignment surgery and how to make screening procedures inclusive for transgender communities. Information must also be accessible to communities typically excluded from care, for example to those in prison and those providing care in prison settings, and provided in multiple languages and formats.

### **How to get more people diagnosed quicker**

Despite work to improve diagnosis, cancer is not always diagnosed early, and sometimes people will receive a terminal diagnosis even if their cancer was detected as soon as symptoms arose. Therefore, it is essential that any plan for the diagnosis and treatment of cancer in the UK includes consideration of palliative and end of life care. The 10-Year Cancer Plan excluding measures for end of life care for patients with cancer is a truly harmful omission.

Hospices and other palliative and end of life care services have seen an influx of patients with late stage cancer across the pandemic. This is largely due to fears of COVID-19 transmission or of burdening the

NHS preventing people from reaching out, as well as difficulty in accessing services during the pandemic. This has placed pressure on providers and affected the type of care these patients receive. Being referred to palliative care specialists at an early stage provides staff with the time to build their relationship with the patient and better understand their needs and wishes. When a patient presents late, end of life care providers have to focus on crisis management, working quickly to manage pain and complex symptoms in the last days of life. Missed diagnoses during the pandemic will result in continuing pressure on palliative and end of life care services in the coming years. The UK's growing and ageing population will also result in more people dying with multiple conditions, including cancer, and complex symptoms. We therefore anticipate an increasing need for end of life care, regardless of measures to improve early diagnosis.

Unfortunately, the lack of a sustainable funding solution for the hospice sector prevents hospices from scaling up their care, investing in innovation or providing maximum value as a system partner to meet the increasing need. Prior to the pandemic, an average of 34% of adult's hospice funding and 18% of children's hospice funding came from the Government, with hospices across the UK having to raise £3.1m of charitable income every single day. There needs to be a sustainable funding solution for the hospice sector if it is to use its capacity and expertise to support the system in responding to the current and expected increase in need.

Plans to increase early diagnosis need to account for an awareness of why some communities have higher rates of late diagnosis than others. Communities who have faced barriers, micro-aggressions and active discrimination in healthcare may be more hesitant to access healthcare when symptoms present. For example, those in secure settings often do not receive equivalent healthcare to what they would receive in the community and therefore symptoms can be missed. We welcome the ambition to introduce measures to reduce inequalities within the 10-Year Cancer Plan and believe it must include an understanding of why late diagnosis is more prevalent in certain communities to ensure everyone gets the best possible care. This focus on inequality must also extend to provisions around palliative and end of life care for cancer patients.

### **How to improve access to and experiences of cancer treatment**

Measures to improve access to and the experiences of cancer treatment in the 10-Year Cancer Plan must include palliative care. Those who receive a palliative diagnosis deserve to receive high-quality palliative and end of life care. Currently, 1 in 4 people who could benefit from specialist palliative care do not receive it. Hospice UK is particularly concerned by the significant rise in deaths in private homes during the pandemic. There have been over 100,000 excess deaths at home across the UK since the beginning of the pandemic and we estimate that almost 67,000 people who died at home in this period have not received the care they need.

At least 80% of hospice care is delivered in the community, including people's private homes, where there is rising need. Not having to be transported to a hospital or other treatment site improves access to care for many patients. In order for more people to receive high quality end of life care in their homes, the Government needs to significantly increase investment in end of life care delivered in the community and commit to ensuring the whole health and social care workforce receives basic training in end of life care. Hospices could be valuable partners in providing such training.

Individual clinicians also need to think about palliative care at an earlier stage in cancer treatment and be more comfortable in including palliative and end of life care providers in discussions about care and prognosis. Earlier access to an end of life care specialist can improve quality of life and studies have found that for people with lung cancer, early introduction to palliative care improved longevity of life.

A 2017 study by Yennurajalingam of patients with advanced cancer found that 55% incorrectly believed that their cancer was curable. In these circumstances, connection to an end of life care provider can help

to manage uncertainty and facilitate nuanced conversations about prognosis and treatment. Sometimes a patient may be receiving treatment but with no clear prognosis or have to choose between potentially life-saving but extremely intensive treatment or moving onto a palliative care pathway. End of life care providers can facilitate these discussions, support Advanced Care planning and ease the transition to palliative care.

Hospices offer expertise in palliative and end of life care but they require support and recognition by Government and Integrated Care Systems to provide maximum value. Hospices provide both inpatient intensive care and out-patient day services to extend good quality life and manage symptoms. Many will also provide clinical support and advice, such as fatigue management and breathlessness clinics, which can improve experiences of cancer treatment. Government and Integrated Care Systems should value hospices as equal partners in the system and involve them in conversations about the delivery of care. The voice of the service user is also key in improving experiences of cancer treatment. We must provide opportunities for them to feedback and be involved in the care they receive and in the local and national development of these pathways.

### **How to improve after-care and support services for cancer patients and their families**

Support services for cancer patients and their families must include the bereavement support someone may need if their loved one dies and support services that can be offered to those that are on an end of life care pathway.

We have seen unprecedented need for bereavement support over the course of the pandemic, with at least an estimated 5 million bereaved. This need continues to grow but funding for the bereavement support sector is insufficient to meet this need. Hospices provide a range of excellent bereavement support services online and in person to around 72,000 people annually and have expanded their services in response to the increasing need, however more support is required. Over the pandemic hospices across the UK have opened up their services beyond those who died in their care, and removed the time window in which people can access support. Individuals are now able to contact a hospice local to them or the hospice where a loved one died and receive bereavement support. North Yorkshire Hospice Care is one hospice with a dedicated specialist helpline, 'Hear to help', which provides support to all those in their local community. The hospice also provides support for Hospice UK's Just B helpline which provides emotional wellbeing, bereavement and trauma support nationally to NHS, care sector and emergency service staff.

Inclusive bereavement support needs to be offered to everyone across the UK who loses someone to cancer and steps need to be taken to ensure equity in access to and quality of care. The Mary Stevens Hospice, with funding from Hospice UK, developed group creative sessions, with the help of an art psychotherapist, which allowed people with cognitive disabilities and who are autistic to explore feelings of loss and grief. Approaches like this should be replicated across the UK but hospices need sustainable government funding to invest in innovation such as this and should not have to rely on charitable grants. Government leadership is also essential to encouraging programmes that promote equity in access, for example, bereavement services for people in prison.

There are various support services offered to those who are receiving treatment on an end of life care pathway. Many hospices, including St Joseph's Hospice and Garden House Hospice, offer a Compassionate Neighbour programme, matching volunteers with those with life-limiting illnesses or who are isolated, to provide friendship as well as emotional and social support. Once again, support services such as this, offered by end of life care providers, require sustainable government funding to be able to continue and support as many as possible and it is concerning that this cancer plan does not account for the support end of life patients will need.

## **How the Government can maximise the impact of research and data regarding cancer and cancer services in England, including translating research and data into practice sooner**

In order to maximise the impact of research and data, Government must improve access to data for organisations and providers, as well as individuals. Cancer research funding needs to support the reduction in the cost of academic content for consumers to enable clinicians to use this research to make decisions about the care they provide and new services. There also needs to be significantly more research on end of life care for people with cancer. Currently less than 0.3% of the £500 million spent on cancer research is allocated to palliative care research. The care needs of people with cancer who have a palliative diagnosis need to be considered when commissioning research at all levels.

A significant challenge that prevents the effective use of data and research is that palliative and end of life care is delivered by a patchwork of public, private and not-for-profit providers and national data systems do not account for this. As it stands there is no consistent collection of hospice data nor any public facing record of it or any consistent data on the communities they serve. As a result, hospice care exists as a blind spot to the system and risks not being an integrated data partner or included in the planning of the delivery of care for people with cancer. There is also data that is available to NHS providers that is not available to hospices, affecting their ability to improve their care and access to it.

It is vital that data collection on the provision of palliative and end of life care for people with cancer takes into account the full spectrum of providers that deliver palliative and end of life care, including hospices. Hospices must also be understood as a key care provider in many terminal cancer patients care journeys and be involved in more open information sharing.

National workforce planning also does not currently use data from across the whole health and care system to make informed decisions. For example, hospices are unable to report on their number of vacancies against an agreed staffing establishment or access the Electronic Staff Record like NHS Trusts. Hospices are struggling with staffing shortages and an ageing workforce and for them to continue to provide a high quality of care to a growing population, their challenges need to be addressed in government workforce planning. Currently hospices lack access to the mechanisms and resources available to NHS staff. Equity in access to CPD training and other opportunities is vital for hospices to retain and attract staff.

Measures to sustain growth in the cancer workforce must include measures to increase staffing in palliative and end of life care to properly support people with cancer with a terminal diagnosis.