appg All Party Parliamentary Group
on Cancer

Minutes
All Party Parliamentary Group on Cancer
Stakeholder Group Meeting

Tuesday 29th November, 17:00-18:00pm, Wilson Room, House of Commons
Chaired by Elliot Colburn MP

Attendees:

Baroness Masham of Ilton
Elliot Colburn MP
Grahame Morris MP
Heather Wheeler MP
Jess Phillips MP
Mark Tami MP
Tim Farron MP

Brad Gudger - Alike
Seren Hughes - Alike
Laura Challinor - Blood Cancer UK
Thomas Brayford - Brain Tumour Research
Jane Lyons - Cancer52
Subodh Tailor – CATTS
Liam Buckley – Less Survivable Cancers Taskforce
Ella Guthrie - Leukemia Care
Bekki Smiddy - Macmillan
Harriette Drew - Macmillan
James Thorneycroft - Macmillan
Julie De Oliveira - Macmillan
Priyanka Patel - Macmillan
Sarah Gilbert - Macmillan
Laura Lee – Maggie’s
Katie Tait – Maggie’s
Zoe Winters – Maggie’s
Chris Warren - NHS England
Mia Western - The Lady Garden Foundation
Megan Fletcher - Sarcoma UK
Alastair Hall - Santander
Sonia Malik - Young Lives vs Cancer
Mel Plumridge

Apologies from:
Tonia Antoniazzi MP
Henry Smith MP
Baroness Finlay of Llandaff
Baroness Walmsley

Agenda:

Welcome and apologies
EGM:
Introduction and background to the financial impact of cancer
Holly Masters, diagnosed with cancer in 2021, and Q&A
Zoe Winters, Welfare and Benefits Advisor from Maggie’s West London, and Q&A
Summary and next steps
Close

Minutes

1) Welcome

As chair of the meeting, Eliot Colburn MP introduced himself and welcomed attendees to the APPGC.

He passed on apologies, and shared his gratitude and thanks to Tonia Antoniazzi for having chaired the APPG so well over the past few years.

2) EGM

Elliot Colburn MP asked for nominations for the new chair of the APPG. Grahame Morris MP proposed Elliot Colburn MP and Jess Phillips MP seconded. Elliot Colburn MP was elected as chair.

Elliot Colburn MP asked for nominations for the vice chair. Grahame Morris MP proposed Tonia Antoniazzi MP and Jess Phillips MP seconded. Tonia Antoniazzi MP was elected as vice chair.

Elliot Colburn MP expressed his excitement in taking over as chair of the APPG and said that he was looking forward to bringing people and groups together to tackle the most pressing issues in the cancer community.

3) Introduction and background

Elliot Colburn MP introduced the topic of the meeting – the cost of living with cancer. Macmillan research shows that 83% of people with cancer in the UK experience some kind of financial impact from their diagnosis. For those affected, this reaches an average of £891 a month. The purpose of the meeting was to gain a better understanding of the causes of the financial impact and possible measures to tackle them.

4) Holly Masters, diagnosed with cancer in 2021

Holly Masters, an actor from Cambridgeshire, shared her experience of being diagnosed with bowel cancer in September 2021 when she was 23 years old. She was unable to work during her treatment which included daily radiotherapy for 5 weeks, due to both the time this took up and also the physical and mental side effects it caused. It would also have been dangerous for her to work during her chemotherapy treatment, as this suppressed her immune system and left her at increased risk from infections like Covid-19.

Baroness Masham asked about the practicalities of receiving treatment and accessing financial support.
Holly said that she was fortunate to live within a half an hour drive of the hospital, but she spoke to others who had been travelling more than 60 miles a day to receive radiotherapy. One friend had to relocate from Bristol to Manchester for 7 weeks to receive specialist radiotherapy, and whilst they were supported financially by family during this time, this was hugely disruptive.

Holly started claiming Universal Credit (UC) just before her treatment started. It took two months to receive a limited capability for work decision and then an additional two months before she began receiving the extra payments for this. She also claimed Personal Independence Payment (PIP) and it took two months from application to telephone assessment, and then an additional month before the payments started.

Holly highlighted that people living with cancer can't afford these kinds of delays if their treatment starts next week. The costs of cancer are immediate – such as increased travel to the hospital and hospital parking charges.

Heather Wheeler MP asked whether hospitals waived parking charges for cancer patients.
Holly had to pay for parking for her hospital appointments, although she was able to par in the disabled bay when undergoing radiotherapy and chemotherapy. She would welcome a national policy to equalise access to parking charges support.

Mark Tami MP noted that finding a space in the car park can also be an issue and that mobility issues linked to cancer treatment can make walking from the far end of the car park to the hospital difficult.

Elliot Colburn MP asked what should be done to improve the situation for people living with cancer.
Holly emphasised that quicker access to support is key and also recommended a purpose-built benefits system for cancer patients. The current system does not fit their experiences or needs – with an example being the PIP assessment, which feels very black and white, and ill-suited to the effects of cancer and its treatment which vary from day to day.

Sarah Gilbert (Macmillan) asked what charitable support Holly was able to access.
As a person under 25, Holly was signposted to the Teenage Cancer Trust and Young Lives Versus Cancer. She was assigned a social worker, who helped her access grants. However, Holly said that people living with cancer should not have to rely on charities to meet basic costs linked to their cancer treatments or to check-ups in the years post-treatment.

Katie Tate (Maggie's) highlighted that they were seeing high numbers of people miss appointments due to the costs of transport and childcare.

Mark Tami MP raised the financial impact on the patient's family and Holly agreed that some people may have to give up work to take care of a relative.

Liam Buckley (Less Survivable Cancers Taskforce) asked Holly how much of the support she had to seek out herself.
Holly said that charities have great information on support, but for those who don't have access to this information and their support, it is difficult to get benefits. This should be taken into consideration within healthcare settings, where patients should be helped to access support which isn't directly linked to their treatment.

Thomas Brayford (Brain Tumour Research) asked whether Holly felt she was treated differently as a young person going through this.
Holly felt like a cancer diagnosis has a huge impact for those who are younger and of working age, and that the benefits system isn't geared towards their situation.

Elliot Colburn MP asked Holly if there was a final message she would like to leave with the group.

Holly drew attention to all the small costs linked to a cancer diagnosis which are not talked about. She has to buy extra food and eat every two hours. She risks permanent nerve damage if her hands are too cold, so uses the heating more. She is at home during the day in winter and uses energy then. There needs to be more awareness raised of these costs.

5) Zoe Winters, Welfare and Benefits Advisor from Maggie's, West London

Zoe Winters explained that she worked in a Maggie's Centre next to Charing Cross hospital. Maggie's have 24 centres at hospitals across the UK and provide benefits advice, as access to psychologists and nurses. She supports people with issues like benefits claims, concessionary travel, grant applications and assessing the suitability of housing.

The people she is seeing are worried about the cost-of-living crisis. The messages about what support is available are not getting through clearly and many don't know if they are eligible for various government and local authority payments. The cost of travel and food has gone up but support payments have not yet increased in value.

Some people are trying to go back to work more quickly post-treatment as the support from the government is slow to reach them and isn't sufficient. There are also fewer people who have critical illness insurance or good income protection from workplace. They have less time to get help in place before their sources of income stop.

Elliot Colburn MP asked what information a patient should ideally receive at diagnosis.
Zoe said that every person's situation is different and that each person with cancer needs expert one-to-one advice about their circumstances. When someone receives a diagnosis and is processing the shocking news, they are likely not thinking about the financial support they can access. There needs to be benefits advice in hospitals to make it more accessible.

Holly reinforced the need to improve awareness and talk about the financial impact from the start, signposting patients to support so they do not receive a nasty shock later.

Elliot Colburn MP asked how good the insurance sector is at fulfilling its obligations for critical illness cover.
Zoe said that their response to a cancer diagnosis is usually good – the support is quick and accessible.

Jane Lyons (Cancer 52) asked what emergency support was available to tide people over until they could access benefits.
Zoe mentioned Macmillan Grants (one-off £350 payments) and Turn2Us which has a generous support fund (up to £1.5k). For many grants, it is dependent on where the patient lives as to what they are able to access. They may not be offered a payment, but rather vouchers for groceries or white goods. Whilst there are many types of grants out there, those who are not computer savvy may not be able to access them.

Ella Guthrie (Leukaemia Care) said that Leukaemia Care had put aside a pot of money for grants to last the calendar year, and they ran out in September. They added an additional £20k to it, but that ran out within the month. As a charity, they have had to change their strategy and priorities to respond to the cost-of-living crisis. It is threatening the ability of smaller charities to offer the services that are needed.

Tim Farron MP asked about the impact of increased waiting times on patients' financial situations.

Laura Lee (Maggie's) said that they had seen more people coming through with a later diagnosis, a worse financial situation and a shortened life expectancy. Longer waiting times also increase patients' anxiety. Previously, Maggie's clients have been worried about their cancer diagnosis first and money second – now, that is reversed.

Some people are also using up savings to pay for private healthcare in order to get their diagnosis and get into the NHS system for their treatment.

Ella Guthrie (Leukaemia Care) asked about what the Household Support Fund is able to offer people.
Zoe said that the nature of the offer and waiting times differ between Local Authorities. Some people may be offered a groceries voucher within 3 days, whilst others have to wait 3 weeks. This causes an overreliance on charities which haven't got the provisions to fill the gap. There is no cancer-support specific fund from Local Authorities.

Elliot Colburn MP asked whether designing benefits and support around cancer patients would help.
Zoe thought that it would and gave the example of the PIP assessment which involves very intrusive questions (e.g. toileting) and can be a traumatic experience.

Holly added that PIP assessors call with no notice, and then ask such detailed questions about your condition that you are made to feel guilty – like you are doing something wrong by having to claim benefits. It is not right that many people are only able to access benefits through very specific advice and support from charities.

It was also pointed out that the benefits system is difficult to navigate for those undergoing a phased return to work. There is not a lot of information about what to disclose and when.

Zoe agreed that returning to work was often a difficult and emotionally fraught time. Many people do not know their rights in terms of reasonable adjustments and employers tend not to be so good at telling them.

6) Next steps

A patient ambassador Blood Cancer UK raised the financial impacts linked to immunosuppression, such as withdrawing from society and not being able to work. Elliot Colburn MP suggested a separate meeting with him to discuss this further.

Elliot Colburn MP thanked Holly and Zoe for their time and the insights they had shared.

Following on from this meeting, the Secretariat will produce a guide of the financial support that is available to people living with cancer. This will be shared with MPs to support with their casework.

There will also be an upcoming officers meeting to discuss how to lobby the government for changes, as well as keeping pushing for the publication of the 10 year Cancer Plan. The officers will also discuss the future work plan and priorities for the short, medium and long term.

Elliot Colburn MP closed the meeting by reiterating his desire to work together with the organisations present to improve cancer care, one of the greatest challenges currently facing the NHS.