



The All-Party Parliamentary Group on Brain Tumours

A record of the minutes for the All-Party Parliamentary Group on Brain Tumours Meeting Grimond Room, Portcullis House - Tuesday 20th November 2018, 17:30 - 18:30

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Chair

Derek Thomas MP (Con, St Ives) was elected to Parliament for St Ives in May 2015. He was elected as the new Chair of the All-Party Parliamentary Group on Brain Tumours (APPGBT) on Monday 10th July 2017, following Rebecca Harris' promotion to assistant Government Whip. He was re-elected into this role at the AGM on 17th July 2018.

Guest Speakers

- Mrs Jenny Farthing – *Supporter of Brain Tumour Research and respondent to the APPGBT's Inquiry*
- Mrs Vicki Hilborn – *Supporter of Brain Tumour Research*
- Miss Jen McCrea – *Young Ambassador for The Brain Tumour Charity*
- Erika Murigi, *Head of Public Affairs and Campaigning, Brain Tumour Research*
- Mr David Peters – *Supporter of Brain Tumour Research and respondent to the APPGBT's Inquiry*
- Mrs Jo Plant – *Director of Fundraising, Headway – the brain injury association*
- Dr Helen Spoudeas – *Paediatric Endocrinologist and founder of SUCCESS Charity*

Attendees

The following Parliamentarians were in attendance.

- Dr Julian Lewis MP (Con, New Forest East)
- Nicky Morgan MP (Con, Loughborough)
- Mark Pawsey MP (Con, Rugby)
- Lee Rowley MP (Con, North East Derbyshire)
- Jim Shannon MP (DUP, Strangford)
- Derek Thomas MP (Con, St Ives)
- Stephen Timms MP (Lab, East Ham)
- Dr Paul Williams (Lab, Stockton South)

Apologies

The following Parliamentarians sent their apologies:

- Debbie Abrahams MP
- Lord Alex Carlile
- Pauline Latham MP
- Baroness Masham of Ilton
- Baroness Morgan of Drefelin

Minutes

Derek Thomas MP, Chair of the APPGBT, opened the meeting, which was held to launch the final report of the APPGBT's 2018 Inquiry into the economic and social impacts of brain tumours. The Inquiry collected over 200 public submissions, received 11 pieces of expert written evidence and heard from witnesses across five oral evidence sessions. He said that the Inquiry had highlighted the alarming gaps in support for people with brain tumours and what needed to be addressed going forward.

A guest from the audience remarked that she thought the report makes practical recommendations. She also raised the economic consequences associated with brain tumours that have lifelong, cumulative impacts. **Derek Thomas MP** agreed, saying that, although there is a good rate of survival in this country, he is disappointed by the experiences that occur after that. He said that a complete lack of understanding of the disease leads to barriers being put in the path of survivors. This lack of support curtails meaningful life chances after diagnosis.

Derek Thomas MP thanked everyone who had submitted evidence into the Inquiry and welcomed the guests, whom he invited to share their experiences with the rest of the room.

In giving her personal account of the illness, one guest argued while his daughter had been given the psychological support she required, it was because she was at the only hospital in the country with a psychiatrist in the oncology unit. This postcode lottery was unfair. Another guest, who is a physician, said she found more education was needed in communities, particularly schools. **Derek Thomas MP** said he'd already had three meetings with Caroline Dinenage MP (Care Minister) to make sure the new 10-year plan doesn't forget to look after people post-disease/illness.

Derek Thomas then prompted questions and comments from the guest speakers. **Jen McCrea** was diagnosed in 2010 and has since had surgery related to the brain tumour four times, contracting meningitis from the first of these. She has managed to raise £10,000 for The Brain Tumour Charity and continues to push issues forward in multiple campaigns. **Jo Plant's** husband, Carlton, was diagnosed with a brain tumour in March 2016 and died later that year. It proved to be an incredibly traumatic experience for her whole family. Due to her connections with **Headway – the brain injury association**, she managed to receive plenty of support, yet, she recognises it is not like this for everyone. **David Peters'** father was diagnosed with a brain tumour in 2007 and died five months later. He felt, at times, the system was actually working against them and treatment options were too limited. **Dr Helen Spoudeas, from the Success Charity**, has worked tirelessly throughout her career in the brain tumour field. She has come to the conclusion that brain tumours must be treated as a brain injury. **Jenny Farthing's** husband had a slow growing, inoperable tumour and died after nine years in her care. She described her husband's situation as a slow progression downhill both mentally and physically and this was not helped by being unable to find support. **Vicki Hilborn** was a survivor of a grade two brain tumour, which she named Phil. She was diagnosed in July 2017 and was upset by the impact current Driver & Vehicle Licensing Agency (DVLA) guidelines had on her life after 'Phil' was removed.

After talk among guests about how humanising brain tumours by giving them a name can help cope with the reality, **Derek Thomas MP** asked the guest **speakers what they believed would have made the biggest differences during their own experiences.**

The two overwhelming answers to this from all guests was better psychological and practical support. **Jenny Farthing** and **David Peters** both believed that a more practical, hands-on-guide following diagnosis would have been enormously helpful. **Jo Plant** also felt that, in her experience, they had been 'left hanging' with very little information. At times they felt they had to battle to find the information they needed. A guest from the audience remarked that a more holistic approach in hospitals was required.

A lengthy discussion then opened up about **how oncologists delivered news to patients and their families.**

Several guests relayed their personal experience of brain tumour diagnoses. Some of the guests felt that it was important that doctors were forthright and honest. Others argued the opposite. Some felt that while it was important to be realistic, some diagnoses were so damning that it would take the patients weeks to get back on their feet and continue the fight. This seemed to be particularly important when children were involved. One guest explained how her son's diagnosis had been delivered rather harshly and he took the news incredibly badly. This apparent bluntness by certain oncologists was a theme echoed by four or five guests. The meeting also heard from another guest, a neurosurgeon, who argued that delivering bad news was always incredibly difficult for doctors. He added that the new NICE guidelines for brain tumours go a long way to improve training, experience and standards for professionals in these skills but is important that they are implemented nationwide and this will inevitably cost money at a time that the NHS has many priorities.

After **Dr Julian Lewis MP** shared a letter from a constituent who was suffering from a brain tumour and not receiving support, the meeting shifted towards a conversation about **access to appropriate help for patients and their families.**

One guest recounted how her daughter was given no Personal Independence Payment (PIP) points by the assessor. This caused unnecessary suffering as their family no longer had enough money to support themselves. **Derek Thomas MP** said that he had spoken to Sarah Newton MP (Disabilities Minister) who had agreed to meet people to talk about their experiences on this issue. **Vicki Hilborn** noted how she was very lucky to have a specialist nurse that seemed to go above and beyond and talk her through the tricky nature of DVLA and PIP assessments. **Dr Julian Lewis MP** suggested that a specialist mentoring service could be set up to support patients to navigate these applications. Another guest suggested this could be achieved by building a community support system that embraced technology. **Jen McCrea** remarked that she was always the youngest person in the waiting room and suggested that more could be done to make time in a hospital a less isolating experience for youngsters.

Derek Thomas asked the panel what was the one thing they would change in the current system.

Jo Plant said that care at an earlier stage was important and there was a need for better palliative care. **Derek Thomas MP** questioned the word 'palliative' suggesting that it takes away the notion of hope. A guest claimed the Dutch were 'onto something exciting' in regards to palliative care and **Derek Thomas MP** said the APPG will look further into it. An oncologist, who had just been in America where he had met with various leading colleagues, said that there was a lot of research taking place globally. He argued doctors worldwide complained that clinical trials were not available in a paediatric setting. Currently, he said, no young children with brain tumours can take part in clinical trials and he argued more must be done to encourage people to get onto them. **Derek Thomas MP** suggested that Lord O'Shaughnessy is working to address this issue.

The guest speakers then continued. **Jen McCrea** argued more must be done to tackle the financial minefield that so frequently follows diagnosis. She recounted how she 'sofa-surfed' a week after her operation as she had no money to rent anywhere for herself. Even now, as an adult trying to buy a house, a 40% deposit is required due to questions surrounding her life expectancy. **Nicky Morgan MP** contributed saying that the Treasury Committee has just launched an inquiry into access to services for disabled people and asked those in the room to supply evidence. **Derek Thomas MP** followed on from that explaining that he had recently joined the House of Commons' Work & Pensions Select Committee and was going to push Frank Field MP (the Committee's Chair) to look into what changes could be made.

David Peters argued while funding and support were clearly at the heart of it all, it is important to not stop trying to find a cure. **Vicki Hilborn** spoke of how funding is the crux of the problem. She also stated that being a brain tumour survivor does not mean you are 'sick' and so should not be treated as such. **Jenny Farthing** felt that psychological help must be provided to improve the lives of the patient and their friends and family. **Dr Helen Spoudeas** spoke about how she would like to see improved services provided for ages 13-30 and briefly mentioned centralising certain services. She also reiterated that brain tumours should be recognised as a brain injury and the need for more neuro-physicians in the field.

Just before things were wrapped up, two new guests revealed their affiliation with brain tumours. Both spoke on how the current system seems to not understand the implications brain tumours can have on the sufferer's immediate family. One lady recounted how she had to work extraordinary hours to cover the hours she missed for her husband's appointments. Another explained how she had been forced to give up her job as a barrister to care for her brother. They had been unable to place him in care as the hospice refused to administer her brother's treatment for epilepsy on top of his medication for his brain tumour.

With proceedings coming to an end, **Derek Thomas MP** thanked everyone who had spoken before handing over to **Erika Murigi**, from the APPGBT's secretariat, who summarised the recommendations the report regarded as possible avenues of progression. These were grouped by themes as: to reduce the financial burden to brain tumour families and their patients, ensure a swift return to independence for brain tumour patients, facilitate increased investment for research into brain tumours and identify ways to improve patient experience.

The room was told there was no date set for the next meeting but it would be in February 2019. After a final contribution from a guest who spoke about her qualitative research into the education experiences of childhood patients in Yorkshire, **Derek Thomas MP** wished everyone well over Christmas.

Actions Arising

- Follow up with Disabilities Minister, Sarah Newton MP, about issues with the PIP process.
- Research the Dutch initiative around palliative care and report back on findings.
- Feed into the Treasury Committee's 'Consumers' Access to Financial Services' Inquiry (deadline Friday 14 December).
- Look into what can be done through the Department of Work and Pensions to improve the experiences of brain tumour patients in relation to some of the aforementioned issues.
- Plan for the education experiences of childhood patients to be explored at future APPGBT meeting.

Needs Arising – as identified throughout the meeting

- An improved process for Personal Independence Payments
- Provision of psychological support for patients and carers
- Improved services for 13 to 30-year olds
- The need for centralised services
- Recognition of brain tumours as a brain injury
- Development of a practical hands-on, support-focused guide
- Make time in hospital a less isolating experience for young adults
- Improvement of palliative care services
- Tackle the financial minefield
- Research the problems surrounding obtaining a mortgage after diagnosis
- Recognition that not all brain tumour patients wanted to be treated as 'sick'