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## The All-Party Parliamentary Group on Brain Tumours

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### A record of the minutes for the APPG Meeting

**Boothroyd Room, Portcullis House, House of Commons**

**Tuesday 1st May 2018, 17:15 - 19:00**

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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 10<sup>th</sup> July 2017.

### Guest Speakers

**Abigail Clement, Grace Latter, Tilly O'Brien, Chandos Green, Jordan Toms** – The Brain Tumour Charity Young Ambassadors

**Dr Helen Spoudeas** - Consultant Paediatric and Adolescent Endocrinologist

### Attendees

The following Parliamentarians were in attendance.

1. Derek Thomas MP (Con, St Ives)
2. Peter Aldous MP (Con, Waveney)
3. Yvonne Fovargue MP (Lab, Makerfield)
4. Pauline Latham MP (Con, Mid Derbyshire)
5. Albert Owen MP (Lab, Ynys Môn)
6. Mark Pawsey MP (Con, Rugby)
7. Chris Ruane MP (Lab, Vale of Clwyd)

### Apologies

The following Parliamentarians sent their apologies:

- Tom Brake MP (Lib Dem, Carshalton and Wallington)
- Caroline Dinéage MP (Con, Gosport)
- Baroness Masham of Ilton
- Baroness Morgan of Drefelin

## Minutes

**Derek Thomas MP, Chair of the APPG on Brain Tumours**, began the meeting by welcoming attendees and explaining that attendees would hear speeches from several of The Brain Tumour Charity's Young Ambassadors on a variety of topics, which would be followed by a question and answer session for each speaker. Mr Thomas read out the apologies and noted that presentations would contribute to the APPGBT's Inquiry into the impact of brain tumours on people's lives.

The first speech came from **Abigail Clement**, who was responding to the question '**What support services are available to young people with a brain tumour diagnosis and where are the gaps?**' Abigail explained that when she was younger her symptoms, such as dizziness and bulging eyes, led to a misdiagnosis initially, and that she was prescribed eye drops. After a fall from high stairs, a scan revealed a brain tumour. Abigail noted that services need to be more aware of the signs of brain tumours, such as sickness, dizziness and loss of weight. An attendee commented that GPs are often unable to diagnose brain tumours as they may only meet one patient with one across their whole career and that we must raise awareness.

Abigail continued by explaining that she moved schools after being diagnosed and then had little to no support from either the council, her teachers or her peers. She explained that she was bullied really badly and left alone to cope. She said her parents had gotten in trouble for her missing so much of school, despite her condition. At one point they were threatened with a two thousand pound fine. She had to go back to school too soon from her treatments, to up the school attendance record.

**Tilly O'Brien**, diagnosed in 2016, followed by answering the question, '**What could be done to improve the transition from paediatric to adult services?**' She began by noting the difference between paediatric and adult services and explained that the transition is difficult, partly due to miscommunication between the services. She explained that she was still being treated in paediatric services, but soon would move to adult services and this worried her as paediatric are much more supportive. She explained that she had not received physiotherapy due to the fact she wanted to be treated in child services.

She said that patients also need to know their psychological as well as physical symptoms but felt she had not been properly assessed for this and therefore she does not know how her brain tumour affects her psychologically. Because Tilly wanted to carry on with her life, she didn't access the full support she might have received if she had otherwise been more obviously vulnerable. She also noted the university gap, when university medical staff are less able to support the needs of students with brain tumours.

One attendee commented that the transition of services involves the opening up of choice. Young people have no choice over where they are treated, whereas older patients do. Tilly was given the choice of where to be treated by her doctors, but this was restricted by her parents. When the time comes for service transition she feels it will be a shock. It was also agreed that young people must be incentivised to take part in and exposed to more clinical trials.

**Chandos Green**, diagnosed initially 20 years ago and having undergone three operations, answered the third question, '**What could employers do to enable young people affected by a brain tumour diagnosis gain employment or stay in work?**' he explained that he found it hard to find a job since leaving university. It is disheartening that employment can't be tailored to patients' needs like university courses can. Now Chandos has to be careful what he gives away in an interview in case it will harm his application, such as not being allowed to drive. Poor memory and physical impairments can limit the likelihood of employers offering you an employment opportunity, compared with someone without these disabilities. It was agreed that young people with brain tumours have vast potential that is currently being wasted. Discrimination laws do not do enough – in his view employers must also think what they can do for the interviewee. Chandos' one ask for employers is to think of ways they can adapt roles to be more accommodating to people with disabilities.

Following a question about career advice, Chandos explained that, throughout his life, people told him he would not succeed, including teachers. He found this difficult and, in most cases, has exceeded expectations, including achieving 9 GCSEs and completing his social care degree. He did need to defer a year at University due to treatment and missed his SATs test, but it worked out ok. Young people with brain tumours have potential, and must be encouraged, but should also be realistic.

**Grace Latter**, diagnosed in 2014 during her third year of University, explained that she had two different experiences of employment. One company treated her openly and very well, but another treated her very

poorly when they found out about her condition. Grace and Chandos both agreed it was better to be open about having a brain tumour with your employers.

Grace, responding to the question **‘What treatment options would you like to see available to young people and what barriers are there currently?’** explained that her symptoms were not taken seriously enough, and she was treated as a ‘silly student’. She had to keep pushing doctors for referrals because she knew something was wrong. Young people are not always given the full picture; in her case, Grace was not the first point of contact and had to be told her diagnosis by her father despite being 21 at the time. This raised questions about patient confidentiality. Grace felt excluded, although she should have been the centre of all communications. Grace agreed that some sort of occupational therapy may have helped her.

Grace’s main ask was for healthcare professionals to take young people seriously. Her experience is of having to be pushy beyond normal reason, for example in relation to the Driving and Vehicle Licensing Agency (DVLA) who she had to call every single day for an update on her driving status.

**Jordan Toms**, diagnosed in 2015 in the final year of university, responded to the question **‘What are the primary issues with the DVLA and how does it impact on your quality of life?’** Following a seizure, Jordan was sent for epilepsy tests and eventually MRI tests, which revealed a brain tumour. Fortunately, his university gave him mitigating circumstances for his studies and he completed his degree. Jordan was treated with both radiotherapy and chemotherapy, but because of the seizure and because the DVLA established his ‘main therapy’ as the chemotherapy, he was told to surrender his driving licence for longer than he felt deserved. Not having a licence impacted Jordan’s life significantly because he felt he lost his independence and relied on his parents to drive him to and from treatment. Jordan was angry that someone who did not know him had decided, unfairly, that he was not fit to drive. Not having a driving licence is also impacting his ability to buy age-restricted products such as paracetamol, due to the lack of photographic ID. He said that there was ongoing confusion about the thresholds for when a licence could be given back and that the situation around brain tumours was treated more severely than, for example, a person clearly at high risk of a heart attack. He proposed that there should be a ‘fitness to drive’ test for all.

Having heard from each of the young people with brain tumours, **Dr Helen Spoudeas** continued the conversation by discussing the work she is undertaking with young people with brain tumours. She recognised that roughly 80% of cancers in young people are cured, but that there is not enough consideration of the brain injuries which occur as a result and what’s the point in ‘providing a cure’, in her view, if you don’t give a life back – perhaps too much effort is going towards finding a cure at the cost of this. It is difficult to attract funding for work to support the transition away from initial treatment to deal with legacy issues. She advocates for the definition of young people with cancer to be patients up to 30 years of age.

It was agreed that there must be investment in visual, speech, language, disability, mental health, hormonal and behaviour services to ensure brain tumour treatment is effective. She suggested that we are collectively missing a trick by not providing more neurological disability support, which is best deployed while the brain is reasonably ‘plastic’. This could be streamlined, with partnerships who help people find employment, following the earlier discussion. Perhaps a new partnership or panel of some kind is required to champion this. Helen finished by saying that a cure alone is not enough.

Following a question and answer session, attendees agreed brain tumours need to be treated holistically and an initiative called ‘Brainbow’ developed by Anna’s Hope, Camille’s Appeal, Tom’s Trust, and more recently, Joshua Tarrant Trust, was put forward as a good example. Dr Helen Spoudeas’ continued view was that research for a cure is important but finding ways to support survivors to be rehabilitated and return to their pre-brain tumour potential is a must.

Closing remarks came from several attendees and included the need to raise awareness, to recognise that each person with a brain tumour has their own lived experience and that brain tumours affect your lives in many different ways. Some questions were left hanging, around whether DVLA decisions can be challenged, and whether there could there be free transport for brain tumour patients and survivors that is not peak-time restricted.

**Derek Thomas MP** closed by telling attendees he plans to raise the DVLA issues with Minister Jesse Norman MP and thanked the guests for attending. The next meeting is planned for 17<sup>th</sup> July 2018.