

Brain Cancer (Children)

Motion made, and Question proposed, That this House do now adjourn.—[Mr. Watts.]

11.19 pm

Jeremy Wright (Rugby and Kenilworth) (Con): Thomas Archer died in his father's arms on 30 October 2005. Thomas, who lived a few streets away from me in Rugby, was a little over two years old, and died of a brain tumour.

In July last year, Thomas became ill and displayed several symptoms that caused his parents concern, including substantial loss of balance. Twice during that month they took him to their local general practitioner's surgery, and twice an ear infection was diagnosed. Antibiotics were prescribed, but Thomas did not get better. Just before the family left for a holiday in France, Thomas was taken to an out-of-hours GP's surgery because his parents were still worried. Again, they were told that there was nothing to worry about. By that point three doctors had diagnosed mild illness, and all three were wrong.

A few days after arriving in France, Thomas was taken to see a French doctor who recommended further tests. Scans revealed a life-threatening medullablastoma in his brain, which was removed the following day. Thomas returned home, but although he appeared to be making a good recovery while subject to chemotherapy, his parents were told on 14 October that his cancer had spread throughout his brain and spinal cord. Thomas died just over two weeks later, some three months after the brain tumour had been diagnosed.

But Thomas's parents, George and Karen Archer, who are sitting in the Public Gallery, are determined that some good should come of their son's death, and it is due primarily to their courage and determination that I sought this debate. Karen and George have already managed to raise over £15,000 for the children's brain tumour research centre at Nottingham university. I pay tribute to them for that, and for what they have already done to raise awareness of this terrible condition. I also pay tribute to their friends and neighbours who did so much to make Thomas's last weeks special, even bringing forward Christmas when it became clear that he would not live to see it, putting up decorations early and arranging for artificial snow to cover the street where Thomas lived.

Thomas was not, of course, the only child to die of a brain tumour last year. Approximately 100 do so every year, and such cancers are now the cause of more childhood deaths than any other disease. The House has debated this important issue before, to the credit of my hon. Friend the Member for Buckingham (John Bercow), who, I am pleased to say, is in his place this evening. He secured an Adjournment debate on the subject on 26 April 2004. I am indebted to him for the speech that he made on that occasion, and also to other hon. Members whose contributions highlighted the many aspects of treatment and support that children with brain tumours, and their parents and carers, so desperately need.

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I do not intend to repeat the points made then, but I commend the report of the debate to all with an interest in the subject. As my hon. Friend said,

"the issue of children with brain tumours is under-debated, under-reported and underfunded."

It was, and it remains so.

Replying to the debate, the then Under-Secretary of State for Health, the hon. Member for South Thanet (Dr. Ladyman), recognised that these matters had been little considered, and said

"I hope that opportunities can be found further to debate them in coming months because they clearly need to be explored."— [*Official Report*, 26 April 2004; Vol. 420, c. 721–25.]

I regret to say that there have been no such opportunities for childhood brain cancers to be debated until tonight.

I do not seek to suggest that no progress has been made in the treatment of cancer generally, or that this debate should be used to condemn the NHS for failing Thomas Archer. I do, however, wish to mention two respects in which I believe that improvements may be made in terms of this highly distressing condition.

First, there is the need to identify childhood brain tumours at an early stage more often. I recognise the great difficulty of diagnosing such conditions, the symptoms of which may be almost indistinguishable from those of other much less serious illnesses, and I cannot judge the general practitioners who failed to do so in the case of Thomas Archer. The fact remains, however, that a French doctor detected brain cancer where three British doctors did not, and, regardless of blame, we should investigate the reasons for that. I hope the Minister will be spurred by this case to think again about what enhancements to the education and awareness of, in particular, family doctors may be necessary.

Secondly, on the importance of effective research, the Minister will know that the NHS spends less on brain cancers than on other cancers, leaving a gap to be filled by the voluntary sector. That, too, is a problem. I understand that national cancer charities spend less than 4 per cent. of their annual research budgets on all forms of childhood cancer. Of course, I understand that the NHS in its current financial state cannot provide limitless resources for the funding of research into childhood brain cancers or, indeed, anything else. We must hope that some of the health research fund that the Chancellor announced in the Budget finds its way to such research. I understand too that, given the relatively small number of childhood cancers compared with adult cancers, there is bound to be a discrepancy in funding, although that compounds the problem, as pharmaceutical companies are also reluctant to invest for the same reason.

There is, however, something practical that the Government can do to help without the need for substantial extra resources. If we look to medical science to provide new treatments for brain cancer in children, the worst thing that we can do is to put obstacles in the path of medical scientists. The strong view of the consultant who treated Thomas Archer is that the implementation of the European clinical trials

directive has damaged such medical research.

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I readily concede that the serious injuries recently caused to one group of volunteers shows the need for some regulation of clinical trials, but it is vital that regulation does not become counter-productive. A recent editorial in the *British Medical Journal* by two Finnish researchers, discussing the impact of the directive Europe-wide, said:

"at the outset many investigators were worried that the labour-intensive, bureaucratic and expensive endeavour of running a clinical trial would become worse. In particular, academic researchers funded by grants, who have so far performed most oncology trials, were worried that their resources might no longer suffice to meet the requirements of the new directive. A recent analysis of research since the directive suggests that many of those fears have been realised".

The authors were referring to a report by the European Organisation for Research and Treatment of Cancer, which showed that clinical trial costs increased by 85 per cent. and that insurance costs doubled, following the coming into force of the directive, resulting in a 63 per cent. reduction in the number of new trials between 2004 and 2005.

Those who suffer from childhood brain cancers cannot afford a reduction in research—they need more of it to be done—so I hope that the Minister will look again at the effect in the UK of the clinical trials directive and cut back on the paperwork, which is costing researchers too many precious hours that could be so much better spent. If those researchers can save more time, they can save more lives.

I ask the Minister to meet the doctors at the Children's Brain Tumour Research Centre, so that she can hear directly from them about the problems that they face. So we are having this debate tonight because Thomas Archer died, but we are also having this debate so that others with the same condition may live. We all share that objective, and I ask the Minister to do all that she can to bring it about.

11.28 pm

Bob Spink (Castle Point) (Con): First, I declare an interest: my son is a neurosurgeon in London.

I congratulate my hon. Friend the Member for Rugby and Kenilworth (Jeremy Wright) both on securing the debate and on the excellent and measured way in which he presented his speech tonight. He has made his case.

We cannot begin to imagine the heartache of those with children taken with a tumour. All hon. Members in the House tonight join my hon. Friend in sending condolences to his constituents who lost their child, Thomas, and we join my hon. Friend in congratulating them on what they are doing to fight to stop others suffering as they did.

My constituents C.A. of Benfleet wrote to me to say that their son died of brain tumour, and they were glad that MPs—certainly all those in the Chamber tonight—were fighting to help to get better research and treatment. They went on to say:

"So many young people seem to get brain tumours and they deserve the chance of life".

They are right. The evidence shows that the number of cases of childhood brain and spinal cancers has doubled in the past 30 years. We need to know why and to solve that problem.

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If I may digress for a moment, one thing is for certain: removing, or causing the removal of, excellent cancer centres that are working well, such as that in Southend-on-Sea, is part of the problem and will not be part of the solution.

I want to raise tonight the specific issue of the palliative care of children with life-limiting tumours. I must first praise the children's hospice movement and the work of the Association of Children's Hospices and its wonderful chief executive, Barbara Gelb. Although I acknowledge that many parents want their children to be at home with them during what is a very difficult time, the children's hospice movement provides excellent respite care and support and enables families to go through this terribly difficult process with some dignity.

The Prime Minister said two weeks ago in this House that the Government are looking at ways to improve the funding of palliative care. Children's hospices in particular need help urgently. They get so little, and many get no NHS funding at all. Their lottery money is running out, and beds will be lost and wonderful care and assets wasted unless the Government act now. Will the Minister write to me explaining how the children's hospice movement's loss of lottery funds will be replaced in the short term, and what longer-term funding structures for hospices the Department of Health is considering? I know that she cares deeply about these matters and will want fair play for these very poorly little angels.

11.31 pm

Mr. Bob Blizzard (Waveney) (Lab): I rise to congratulate the hon. Member for Rugby and Kenilworth (Jeremy Wright) on securing this debate this evening, following as it does the debate initiated just under two years ago by the hon. Member for Buckingham (John Bercow), through which this important issue was brought before the House for the first time.

I want to draw to my hon. Friend the Minister's attention the continuing work of the Ellie Savage memorial trust in my part of the country. Ellie Savage was a young girl, a constituent of mine, who sadly died from a brain tumour. In her memory, her family formed this charity. To date, it has raised more than £150,000 and it is using that money to fund a three-year research project into new ways of treating glioblastoma multiform, a most aggressive form of brain cancer from which Ellie sadly died. The trust is also piloting a rehabilitation programme in partnership with Addenbrooke's hospital. It is the first to recognise that although children who are recovering from

brain tumours may have overcome the tumour itself, they can be left with devastating deficits. The trust wants to educate the schools and families of those children, so that they are best able to support them.

The trust exists primarily to give financial support to families who suffer this tragedy. It is a question not only of caring for the suffering child, but of the unpaid leave that is sometimes involved in caring for siblings. The trust supports those families, including with travelling expenses.

What the Ellie Savage memorial trust is asking for from the Government is more support for the research to which the hon. Member for Rugby and Kenilworth

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referred, and that they also encourage primary care trusts to work in partnership with such voluntary organisations, particularly on rehabilitation. PCTs should be embracing these voluntary bodies and supporting them; that way, together, we can give these families some hope.

11.34 pm

John Bercow: I follow colleagues in congratulating my hon. Friend the Member for Rugby and Kenilworth (Jeremy Wright) on raising this issue in terms that were measured, responsible and dignified, yet at the same time quietly passionate.

I should like, if I may, briefly to make a number of other points. First, there is now a substantial body of serious research that suggests that a combination of radiotherapy and the use of temozolomide can significantly enhance survival rates for patients newly diagnosed with glioblastoma. Ministers need to take account of that fact to which they need to respond.

Secondly, Roy Rampling, professor of neuro-oncology at the Western Infirmary in Glasgow is one of 36 consultants and specialists who have written to the Secretary of State for Health to argue that the use of temozolomide and carmustine implants is effective and represents value for money. They are challenging the judgment of the National Institute for Health and Clinical Excellence, which has made a preliminary recommendation against the use of such treatments. They, with their expertise, believe that is wrong.

Thirdly, and finally, we have to take account of the views of those experts. Professor Rampling believes that the treatments to which I referred represent the biggest breakthroughs in the treatment of brain tumours in 30 years. We are entitled to ask the Minister, in the most sincere terms, why between two and three times as many people are being treated with temozolomide in Canada, France, Germany, Italy and Spain. Their doctors obviously think it makes sense.

My appeal to the Minister is that she will consider the possibility that a wrong judgment has been made, keep an open mind, and listen to the evidence. Could there be a better way for her to do so than to come before a meeting of the all-party group on brain tumours, of which I am privileged to be chairman, where she could hear the

arguments from those infinitely more expert than I will ever be and be offered the opportunity to respond?

11.36 pm

The Minister of State, Department of Health (Ms Rosie Winterton): I congratulate the hon. Member for Rugby and Kenilworth (Jeremy Wright) on securing the debate, which has highlighted the tragic case of Thomas Archer and the courage and determination of his parents. I hope that the hon. Gentleman will allow me to express my deepest sympathy to them. The fact that we have quite a crowded Adjournment debate shows the importance attached to the issue.

Before I turn to some of the specific points that the hon. Gentleman made, I shall provide some background information about cancers among children. In the difficult circumstances of the debate, this is difficult to

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say, but, thankfully, cancer in children is rare and there have been remarkable improvements in survival rates over the past 30 years. Some of that improvement has been due to technical advances and the centralisation of care in specialist centres, as well as the hard work of clinicians and researchers. Seventy-five per cent. of children with cancer can now be cured, but I recognise that although survival rates for children diagnosed with brain tumours have improved in recent years, they are not, as the hon. Gentleman said, as high as for some other childhood cancers.

The hon. Gentleman gave an extremely moving account of what happened to Thomas Archer. I hope he will understand that it is extremely difficult for me to talk about individual cases, but I can assure him that I certainly recognise the need to ensure that the signs and symptoms of cancer are picked up as soon as possible so that a quick and accurate diagnosis can be made. To put that in context, a GP will see on average only one child under 15 with cancer every 20 years, yet they will see many children each week with a wide variety of symptoms that could be cancer. It is important to recognise that they have a difficult job to do. In April 2000, we tried to support GPs in that respect by issuing "Referral guidelines for suspected cancer", which aimed to help them to identify patients, including children, who were likely to have cancer and so required urgent assessment.

After the debate in 2004—I pay tribute to the hon. Member for Buckingham (John Bercow) for initiating it—the guidelines were updated by the National Institute for Health and Clinical Excellence and reissued in June 2005. That had been raised during the debate. The guidelines include a section on cancers in children and young people and specifically try to address the signs and symptoms of brain tumours. The Healthcare Commission is currently consulting on how to ensure that those standards are implemented across the country, so that there is consistency. I fully appreciate that that will not be of comfort to Thomas's parents at this point, but I hope that it shows that action is in hand to ensure that GPs are alert to possible symptoms of cancer in children and are able to act accordingly.

The hon. Member for Rugby and Kenilworth also raised the issue of research into brain tumours. Again, that issue was raised in the 2004 debate. My Department has

established the national cancer research network, which considers specialist research work on paediatric oncology. The network has a dedicated brain tumour group, which is currently running a range of studies on the diagnosis and treatment of brain tumours in children. Separately, my Department funds the childhood cancer research group at Oxford university, which maintains the national registry of childhood tumours. That is the largest population-based childhood cancer registry in the world. The Department also supports a senior clinical research fellow at Birmingham university to study a comparison of magnetic resonance spectroscopy and tumour genetics in childhood brain tumours.

I know that we can always argue for more research into particular cancers, but I hope that I have been able to give some reassurance that particular research into childhood brain tumours is being carried out. Research into other childhood tumours can help our understanding in this area, too. I assure the hon.

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Gentleman that I will ensure that the National Cancer Research Institute is aware of the points that hon. Members have made.

In addition, the hon. Gentleman raised some concerns about the clinical trials directive. As he acknowledged, it is important that we have in place proper protection for those participating in clinical trials, because of the risk that the trials may pose to individuals. I can assure him that we will assess the effects of implementing the directive, including a consideration of whether it is over-bureaucratic, as soon as reliable evidence is available. I will certainly take up his offer to meet the doctors he mentioned.

The hon. Member for Buckingham expressed concern about NICE's preliminary recommendations, in December, on the use of carmustine implants and Temodal in the treatment of newly diagnosed high-grade glioma. Those recommendations were subject to a period of consultation, which ended on 1 February, and NICE's final recommendations are, as he said, expected to be published in August 2006. Those final recommendations can be appealed. NICE is an independent body, which we rely on to produce clinical and cost-effective guidance to the NHS—based on the latest available evidence and having considered the comments that it receives during consultation. It is difficult for Ministers to comment on some of these issues, but I will certainly take up his offer to meet the group that he talked about. As I have said, the recommendation is not the final one and, in the meantime, primary care trusts have the discretion to fund the treatments outwith the final recommendations.

Points have been raised in the debate about the way in which services for children with brain cancer are organised and staffed. Again, those points built on some of the issues raised in the 2004 debate. In August 2005, NICE produced service guidance on how the NHS could improve services for children and young people

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with cancer, including those with brain tumours. The national cancer director has established a group, which he co-chairs with the national children's director, to help to

implement the guidance. The group will certainly consider several of the issues raised by my hon. Friend the Member for Waveney (Mr. Blizzard), especially the need for members of the voluntary and charitable sector, such as the Ellie Savage memorial trust, to work with the NHS. I assure my hon. Friend that I will ensure that the two co-chairs of the group are aware of the ideas that he put forward in the debate so that they can examine them closely.

The hon. Member for Castle Point (Bob Spink) raised the issue of children's hospices. I am sure that he is aware that we made a number of commitments in our manifesto on how to increase palliative care, and we will make further announcements on the matter, including on children's hospices. I am well aware of the point that he raised and certainly undertake to write to him about it.

I hope that I have been able to give some reassurance to hon. Members who have spoken in the debate and, indeed, to Thomas's parents, who, as the hon. Member for Rugby and Kenilworth said, have been campaigning, raising money and trying to raise awareness. It is tribute to everyone who has spoken in the debate that they have added to that awareness campaign. There is certainly still more than we need to do to improve services for children with brain tumours, but we have set in train several actions, which have arisen because of points that hon. Members have made in the House previously. I hope that those actions will bring about change in an area that anyone who has heard the debate will realise is extremely important and something that still tragically affects too many children and, of course, their parents.

Question put and agreed to.