

Epilepsy Debate – House of Commons

26th February 2015

3.6 pm

Laura Sandys (South Thanet) (Con): I beg to move, That this House has considered epilepsy. I would like to start by thanking the Backbench Business Committee for allowing my right hon. Friend the Member for Chesham and Amersham (Mrs Gillan), who has done so much to support and advocate on behalf of people with epilepsy, and me the opportunity to have this debate. It is a great honour to be able to open this debate in the presence of so many fellow members of the all-party group on epilepsy, who over the past five years have worked together to ensure that we raise epilepsy issues with all the relevant Departments. However, I personally feel that I might not have done enough. There is still so much more to do to ensure that epilepsy has its rightful place in health and social care and that it is seen as a chronic condition that needs greater attention, greater support and—this is very close to my heart—much less stigmatisation.

Mr Mark Prisk (Hertford and Stortford) (Con): I am grateful to my hon. Friend for giving way and sorry to interrupt quite so early in her speech. I strongly support her and my right hon. Friend the Member for Chesham and Amersham (Mrs Gillan) in securing this debate. Like my right hon. Friend, I am blessed by having a national epilepsy centre in my constituency, but I still have constituents who worry about stigma. In particular, Rachel Dawes and Susan Gayler feel that even now, despite having a national centre of excellence locally, the issue of stigma is important? Does my hon. Friend agree?

Laura Sandys: I most certainly do. Addressing stigma is at the heart of the treatment, care and, frankly, funding for epilepsy. Too often it is swept under the carpet. For example, statistically there should be many more Members of Parliament who have declared themselves as having epilepsy. That is because of the stigma and the overall environment for people like me—I am a sufferer, as is my hon. Friend the Member for Blackpool North and Cleveleys (Paul Maynard)—so no doubt there are more Members of Parliament who have epilepsy.

Sir Bob Russell (Colchester) (LD): Part of the training for first-aiders is how to deal with epilepsy. Does my hon. Friend agree that if first aid were part of the school curriculum, more people would be able to deal with such situations?

Laura Sandys: I know that first aid in schools is an issue that the hon. Gentleman is very passionate about. I absolutely do agree. This condition impacts one in every 100 people; it is a very large-scale chronic condition. When a child falls to the floor in school, they need people who are confident to deal with them—who know what the issues are, can calm the rest of the classroom, and understand that this can be managed and supported. If people in authority do not know how to respond—we have examples among the police, those in schools, and even nurses—they feed the stigma, feed the problem, and feed the anxiety around people with this condition. I feel that we have not done enough to push for greater change and greater focus, and to ensure that Government and the charities have greater ambition for people with epilepsy. However, I think we have done a reasonable amount, and I hope that over time we will do much more in this place and outside.

Stigma is one of the problems. Epilepsy is not trendy; it is not a fashionable condition. It is not information that people volunteer when they make a job application. I can assure Members that one does not talk about it as a set-piece at social events when describing an illness during the week. People with epilepsy frequently try to disguise it; we can see it in their eyes. I have always been very clear about it, because I believe that we should take away the stigma. We cannot normalise it,

because it is not a normal condition, but we can make it something that needs to be addressed in equality with other chronic conditions.

Kate Hoey (Vauxhall) (Lab): Does the hon. Lady think it shocking that in this day and age a very large public body like Transport for London—London Underground —could sack a young woman for the fact that she has epilepsy? Does she agree that we cannot allow this to happen?

Laura Sandys: I very much welcome that intervention. I was going to mention that case, which is extraordinary for two reasons. First, why would the young woman lose her job? She already had the job and was succeeding in it, so why was the sudden revelation of her epilepsy a reason for losing it? Secondly, her manager said that it had absolutely no impact on her ability to perform her role.

This is, in many ways, a 19th-century attitude. It is the expectation that when one tells somebody that one is epileptic, they expect one to be dropping to the floor foaming at the mouth. Many in this Chamber may not know that until the 1970s I, as an epileptic, would not have been allowed to marry—although I am sure that many did because they did not declare that they had epilepsy. That is the sort of stigma that we were dealing with not so long ago. It is a Dickensian, 19th-century perspective. I believe, fundamentally, that that lies a little at the heart of why, for a chronic condition that impacts one in 100 people—more than many other conditions—epilepsy does not get the right level of attention. This is an important task for us here in the Chamber and for the all-party group on epilepsy, and for me to continue outside this place. Many other conditions have overcome embarrassment and stigmatisation. It is absolutely crucial that we start to address this through our public services, our schools and education system, and our hospitals and GPs.

It is important that those of us with epilepsy are much more vocal. I hope that the Serjeant at Arms will not come and arrest me, but my hon. Friend the Member for Blackpool North and Cleveleys and I have actually broken the rules of the House. We did not exactly sneak up Big Ben, but we broke the very clear rules saying that anyone with epilepsy is not allowed to go and look at it. We thought, “You try and catch us!” We broke the rules of the House, and went up to the top. We have used that as a platform for saying that we should both contest it when epilepsy is not supported effectively enough, and challenge people who do not understand epilepsy enough and are fearful of those who have it. We think it took 150 years for somebody with epilepsy to go up Big Ben, and we are trying to identify other rules that we can break, so if hon. Members hear that my hon. Friend and I have got into trouble, they will know what it is all about.

Epilepsy has a very wide range of symptoms. I am very lucky to have very mild epilepsy. It is controlled and I am on medication, so there is no issue and I am very unlikely to have a seizure. However, it is incumbent on people such as me to be a voice for people who are suffering, and who may have a seizure every 10 to 15 minutes. I know that my right hon. Friend the Member for Chesham and Amersham, like Young Epilepsy and Epilepsy Research, very much focuses on people with chronic epilepsy. Such people do not necessarily have a voice, and it is for us to make their voice heard.

The issue that has arisen in relation to the lady from London Underground is not the only example. Several people have e-mailed their Member of Parliament and asked me to raise their concerns. A young woman with a masters degree cannot find a job because employers say that she has declared she has epilepsy and they are concerned that she may become a problem for the company. That has now happened 12 times, but it must not continue. We must ensure that employers, the police and hospitals—even in a hospital, someone having a seizure has been accused of being drunk and disorderly—understand people with epilepsy and recognise their condition for what it is.

Mrs Cheryl Gillan (Chesham and Amersham) (Con): May I congratulate my hon. Friend on leading the charge in getting this debate? She will be very sadly missed in this place, where she has made a tremendous contribution. Does she agree that it is very important to understand more about the condition of epilepsy? Another area in which I take a great interest is autism, and it is estimated that 46% of children with autism also have seizures. Does she agree that we do not yet know enough about the relationship between epilepsy and other conditions, such as autism, to enable us to succeed on behalf of such people?

Laura Sandys: Absolutely. I totally agree. In many instances, people with epilepsy also have other chronic conditions, which are no doubt contributory factors. The level of support for research on epilepsy is significantly lower than for other conditions. Again, it is seen as a secondary or tertiary priority when it comes to research funds. It is absolutely crucial to understand the interrelationship between epilepsy and autism, as well as between epilepsy and school achievement and all sorts of not only chronic conditions but life-restricting—as well as life-enhancing—problems. I believe that we need a lot more research, but this comes down to people being clear that epilepsy matters.

Steve Rotheram (Liverpool, Walton) (Lab): On that point, I have had correspondence with a hospital in my constituency called the Walton neuro centre. It says that neuropsychological care is very important, especially for younger people who, if they have access early enough, have the propensity to go on and achieve their full potential. Does the hon. Lady agree that Ministers should consider what more they can do on access to such neuropsychological assessment and care, and in supporting the work of the Walton neuro centre?

Laura Sandys: Absolutely. There are some wonderful, excellent centres in constituencies around the country, including in the hon. Gentleman's constituency, but there are too few of them and there is not enough immediate referral to tertiary care once a GP identifies that epilepsy might be at the heart of a problem. We need to ensure that there is a greater understanding at the core of our health sector so that there is more referral. To be frank, we need more specialists. There is a major problem in the referral process. Epilepsy Action says that 138,000 people have been misdiagnosed. Some people are diagnosed with epilepsy who do not have it and others do not have the right medication. It is crucial to address the huge problem with referrals to tertiary care.

Following diagnosis, the cost-effective and life-enhancing pathway is to ensure that the ongoing care fits the bill. There are straightforward National Institute for Health and Care Excellence guidelines that lay out a clear pathway. There must be access to an epilepsy nurse. It would be fantastic if more GPs had epilepsy as a specialism. There must be a wrap-around package that allows people to live their lives and take control of their chronic condition. We must ensure that we have the right level of support at every single level. I am talking about people who are still potentially going to work and living their life.

We have a serious problem with SUDEP, or sudden unexpected death in epilepsy. That is an outrage. About 1,000 people every year die in their sleep. Many of them are younger people who are just moving from youth to adult services and there is not the wrap-around care that is needed. We all know from our casework that in every instance and with any condition, moving from youth services to adult care is a problem. We are seeing serious problems with those who have night-time seizures. To be frank, although people say that that is a problem, there are examples of countries in Europe that are doing better. It is crucial that we meet those targets and ensure that we do not fall behind the standards of other European countries.

I see that Mr Deputy Speaker is looking for me to wrap up. I would like to commend three sets of people, but also to challenge them. People with epilepsy live with a difficult and unpredictable

condition. I take my hat off to them and to the people who care for them. However, I want them to come out and talk about epilepsy. I ask them to please ensure that their voice is heard, because if it is not, we will not get the care that we need. The charities are important, but they need to work together more. Their voices must be unified to ensure that they are heard. I call on the Government to address the Cinderella status of epilepsy. We should be doing so much better. We have criteria and there are examples, globally, of countries that are doing better. We must give people with epilepsy a lifeline to ensure that they can live a full life, and we must put the right level of investment into research to address chronic epilepsy in the long term.

Several hon. Members *rose*—

Mr Deputy Speaker (Mr Lindsay Hoyle): Order. I am bringing in an eight-minute limit. I call Kate Hoey.

Kate Hoey (Vauxhall) (Lab): Thank you, Mr Deputy Speaker. I will certainly keep to that time limit. I welcome the debate and congratulate the hon. Member for South Thanet (Laura Sandys) and the right hon. Member for Chesham and Amersham (Mrs Gillan) on making it happen. As Members will know, I had an Adjournment debate on the subject on 29 January 2013, just after the report “A Critical Time for Epilepsy in England” had come out.

The hon. Member for South Thanet covered a wide range of points, all of which I agree with her about, particularly the stigma of epilepsy. That is a crucial point, but I will not go over all of what she said. I want to use this opportunity to ask the Minister various questions. He kindly responded in detail to the Adjournment debate, when we had slightly longer than half an hour, and I thought it would be helpful to follow up on a number of the issues that were covered.

I want to ask the Minister about the progress that has been made on urgent referrals, about which I and a number of other Members have been concerned. As I understand it, referrals are in theory currently meant to take two weeks, but I have had constituents who have had to wait well over two months. I want to check what the Minister is doing to urge commissioning groups and others to speed that up, because it really makes a difference if someone is seen as quickly as possible.

Part of the problem in looking at epilepsy is the lack of understanding throughout the country. Many people do not say that they have epilepsy of one form or another, but it is amazing how many times, when it comes up in a conversation, people say, “Oh yes, my cousin”—or uncle or whoever—“has epilepsy”. There is always somebody, because the numbers are very large. Will the Minister say something about that?

As I mentioned in the previous debate, a significant number of people with epilepsy have avoidable seizures. If the correct treatment is given at an early stage, that consequence can be avoided, which prevents benefit dependency, the loss of employment or people having to give up education due to a lack of support.

Will the Minister confirm what progress his Department has made on some of the other issues that were raised in my Adjournment debate and previous debates, and by my hon. Friend the Member for Walsall South (Valerie Vaz) when introducing her ten-minute rule Bill, which I am sure she will want to mention? There is a stigma to epilepsy, but we have to promote the positive fact that so many people with epilepsy live perfectly normal lives which we would all be proud of and happy with. Will the Minister make a commitment that the disabled freedom pass and disabled railcard will continue to be available to those with epilepsy? Will he reassure anyone who is watching that that important support will definitely be kept?

Epilepsy constitutes a disability under the Equality Act 2010, and as such, employers are required to make reasonable adjustments so that employees suffering from epilepsy can stay in work. Epileptic episodes are often triggered by work, particularly when an individual is working long hours or is otherwise under stress. However, people suffering from epilepsy are perfectly able to function at the highest levels, and in many cases can successfully medicate to reduce or entirely eliminate the occurrence of attacks. Almost three quarters of people suffering from epilepsy can be free of seizures once they find the most appropriate medication. Women of child-bearing age are restricted in the drugs that they can take, and people who first suffer from epilepsy in early adulthood often take a long time to adjust to the condition and make changes to their lifestyle.

I want to draw the Minister's attention to the case of London Underground worker Karen Guyott, which was mentioned earlier. She is 29 years old, and she was diagnosed with epilepsy about five years ago. She has now been dismissed due to her epilepsy. Karen was one of a number of London transport staff suffering with epilepsy—I think that 16 are London Underground operational staff, and there are a further 11 working for Transport for London.

London Underground's original response to Karen's diagnosis was to attempt to dismiss her right away using its capability procedure. The National Union of Rail, Maritime and Transport Workers successfully fended off that attempt, and instead got London Underground to make reasonable adjustments. Now, as I said, she has been dismissed, and I think the Minister should look into that and review it.

Karen's attendance record was exemplary, and in January this year during an episode, one of her colleagues moved her from a place of safety and left her outside a locked station supervisor's office that was close to an escalator. Karen became disorientated and wandered towards the escalator, but her colleague realised the danger and moved her into the office. As a result of that incident, instead of providing training for Karen's colleagues, London Underground argues that Karen's condition is too risky for it to manage, and it is clear that it is no longer willing to accommodate her. Karen is a prominent trade union activist, but if London Underground is using epilepsy as an excuse because she is a trade union activist and it does not like her or some of the things she says, that is even more shocking.

London Underground agreed to undertake a further risk assessment that amounts to an additional requirement on Karen to which other employees without epilepsy are not subject. Since then Karen has been dismissed, but London Underground insisted that she could not work at any station that had a public highway attached to it or any escalators or stairs. Everything she did required a "zero-risk" policy—the risk had to be eliminated —and such an approach is out of step with London Underground's usual policy.

London Underground's equality and inclusion procedure states that employees who develop conditions during their working life must be transferred to a suitable position. As a huge public sector employer that has signed up to all legislation on equality and equal rights, London Underground should have made more effort to keep Karen employed, because with a modest amount of training that support can be provided. Given the risks that London Underground deals with regularly, a member of staff temporarily struggling to manage a relatively newly diagnosed but easily treatable condition would seem to be at the lower end of those risks.

A recent employment appeal tribunal, *Dyer v. London Ambulance NHS Trust*, stated that the duty to make reasonable adjustments must always be carefully considered, and that only in the rarest of cases could no reasonable adjustments be made. That affirms that even when it

comes to epilepsy, the duty to make reasonable adjustments could extend to redeployment with the additional support of the Access to Work programme. A lot more must be done and London Underground must be put on report.

Mrs Cheryl Gillan (Chesham and Amersham) (Con): It is an honour to follow the hon. Member for Vauxhall (Kate Hoey), and I hope that she obtains justice for her constituent. It is also an honour to follow my hon. Friend the Member for South Thanet (Laura Sandys). As I said earlier, she will be a great loss to the House, and I am personally sorry that she is leaving this place because I think she has added a great dimension to it, particularly on the subject of epilepsy.

I declare an interest because the Epilepsy Society is based in my constituency and I am proud to be a vice-president. It has been working with and for people affected by epilepsy for 123 years. Although the detail of its aims and objectives have altered over the years, fundamentally it remains true to the vision set out by the group of philanthropists and neurologists who established it in 1892—to cure, treat and prevent epilepsy. It is unique.

At the Epilepsy Society's Chalfont centre, groundbreaking epilepsy research laboratories are co-located with England's only dedicated epilepsy assessment and treatment centre. Led by medical director Professor Ley Sander and head of genetics Professor Sanjay Sisodiya, some of the world's pre-eminent epilepsy researchers and clinicians undertake research and clinical practice at the Chalfont centre. The Epilepsy Society's researchers have been central to new scientific discoveries, in particular research that demonstrates the breadth of genetic influences in epilepsy. The society also brings together state-of-the-art diagnostic tools for epilepsy in one place, including the UK's only dedicated epilepsy MRI scanner and a specialised epilepsy therapeutic drug monitoring service that is provided to hospitals across the UK and Europe.

The Epilepsy Society is also part of a unique three-way partnership with the NHS and with academia—the national hospital for neurology and neurosurgery at University College London—that has the benefit of translating research into clinical practice, providing access to funding, attracting top researchers and clinicians and providing the flexibility to innovate. The partnership has been recognised by the World Health Organisation.

Steve Baker (Wycombe) (Con): My right hon. Friend has taught me something today—I did not know that my constituency was adjacent to such a fantastic centre. Will she confirm that it is a national centre serving a population wider than just our constituencies?

Mrs Gillan: That is absolutely right—it is a national centre.

Under our new chair, Helen Pernelet, and the new chief executive, Angela Geer, the Epilepsy Society has an ambitious new vision to leverage its medical research strength to revolutionise how epilepsy is diagnosed and treated. Of course, there are issues facing the society's specialised medical and research facilities, but sadly, with only eight minutes in which to speak, I might not get through them all. For the Minister, there are co-commissioning concerns. Under the Health and Social Care Act 2012, the responsibility and budget for specialised services were brought together in NHS England as the sole national commissioner of specialised services, but since May 2014, it has U-turned on national commissioning. Instead, the new proposals for co-commissioning would see responsibility for the vast majority of specialised services shared with local clinical commissioning groups.

The Epilepsy Society is opposed to the co-commissioning of specialised epilepsy services for several reasons. NHS England asserts that national service specifications will continue to apply to co-commissioned specialised services, but it is uncertain how that will be achieved, given that CCGs are independent bodies. If CCGs are allowed to reinvest savings from specialised commissioning in other areas of their budget, it might create an incentive to underspend on specialised services, raising

questions about the level of investment. There is also evidence that CCGs are not in a position to engage with specialised commissioning in areas such as neurology. For example, the Minister will know that the Neurological Alliance's recent report, "The Invisible Patients", found that only 26% of CCGs had assessed the prevalence of neurological conditions locally and that only 14% had assessed the cost of neurological services.

I also wish to highlight the Epilepsy Society's opposition in principle to the introduction of a marginal rate in specialised commissioning and its concern about the lack of clarity in neuroscience specification. There is an ongoing lack of clarity over the division of responsibility between NHS England and CCGs for commissioning neurological services, and there is continued confusion about precisely which services fall under the scope of specialised commissioning arising from inconsistent statements in the manual for prescribed specialised services and the neurosciences service specification. I hope that the Minister can respond to the society's calling on NHS England to clarify this important service specification to ensure nationally applied standards for specialised epilepsy services.

I encourage the Minister to improve access to the Government's flagship 100,000 Genomes Project. It is an exciting development that the Epilepsy Society strongly supports, but the project's focus is largely on cancer and rare diseases, making it unlikely that more than a handful of epilepsy genomes will be sequenced as part of the groundbreaking initiative, despite the huge potential that genome sequencing has for transforming epilepsy. I would like to see the Government continue to invest in genetics research and its translation into clinical practice and to ensure that it benefits patients with epilepsy, but I would particularly like to see the genome project embrace epilepsy.

The need to reform the current system for accessing effective medicines will become ever more important in the context of increasing the availability of personalised medicines. I have been working locally with Daiichi Sankyo on patient access to novel oral anticoagulants, and there is a gap that the Department of Health needs to address across the board.

In my remaining minutes, I would like to draw attention to the issue of laser ablation surgery. I have recently dealt with a distressing case of a constituent who sadly lost a family member to epilepsy. The constituent expressed great distress that a surgical treatment known as laser ablation therapy had not been made available to her and her child as a treatment option. Laser ablation is a relatively new surgical technique that burns away accurately targeted tissue with a surgical laser. The technique is much less invasive than traditional brain surgery, and enables surgeons to operate deeper in the brain. It is also much more accurate and carries fewer risks of complication. Laser ablation can be a good choice for patients who have few other treatment options either because medication does not control their seizures or because the lesions in their brain that cause their epilepsy are deep and hard to reach using open brain surgery.

A significant minority of epilepsy patients—approximately 12,500 in the UK—would benefit from surgical treatment, including laser-guided surgery. In around 60% of these cases, surgery can be curative. Evidence shows that it also contributes to reducing premature mortality in epilepsy. Sadly, despite these benefits, only around 300 patients a year are currently given this treatment. I think that the Department of Health should urgently review the number of patients with access to neurosurgery each year, particularly surgery that uses the new and less invasive techniques such as laser ablation.

Finally, I mentioned the connection with autism, to which my hon. Friend the Member for South Thanet responded during her opening speech. It is obvious that although we have made great strides on epilepsy since the days when epileptics were not allowed to marry, we still have a long way to go.

I hope that the Minister will respond positively to the questions raised on both sides of the House about the future of epilepsy in the hands of the NHS.

Teresa Pearce (Erith and Thamesmead) (Lab): First, I congratulate the hon. Member for South Thanet (Laura Sandys) on securing this debate and on continuing to raise awareness of epilepsy. Although we are on opposite sides of the Chamber, I am sad that she is leaving this place after May, as the work she has undertaken on behalf of people with epilepsy is much respected both within and outside this House.

Epilepsy is a life-threatening, neurological condition that can strike anybody at any age without warning. However, being a woman with epilepsy is not the same as being a man with epilepsy. Epilepsy and its treatment can affect sexual development, menstrual cycles, contraception, fertility and reproduction. That is why I am taking the opportunity today to talk about the urgent need to improve the support and advice available to women of child-bearing age who have epilepsy. In particular, I would like to highlight the importance of enabling women to make informed choices about their drug treatments.

Approximately 139,000 women of child-bearing age have epilepsy, and around 2,400 babies are born each year to mothers taking these anti-epileptic drugs yet women with epilepsy remain uninformed about their choices and medication. They lack the specialised care and support they need, and they are at increased risk of maternal death. Given the repeated concerns raised over decades about sodium valproate and its links to the development of birth defects and foetal anti-convulsant syndrome, commonly known as FACS, this is nothing short of a scandal.

The use of anti-epileptic drugs can present women with various problems before conception and during pregnancy. National guidelines indicate that women of child-bearing age with epilepsy should be made aware of the impact their medication could have on their unborn baby. While GPs should be highlighting these risks, the provision of this specialised care and information is variable at best and non-existent at worst—and this despite the fact that in 2012 the National Institute for Health and Care Excellence recommended a new indicator to encourage GPs to tell girls and women of child-bearing age about the risks posed by anti-epileptic drugs. Sodium valproate was specifically named as a drug that should be discussed.

Is the Minister concerned that this information is not widely distributed, and what steps will the Department of Health take to ensure this is remedied as a matter of urgency?

Sodium valproate is considered to be one of the most effective drugs for controlling epileptic seizures, but it has been found to increase the risk of babies being born with cleft palates and spina bifida. It is also associated with a very high risk of major malformations and neuro-developmental impairment. Despite that, a survey found that 25% of mothers were unaware of the risks, which is unacceptable and unjustifiable. If we know that the medication can cause so much harm—it is also prescribed for women who do not have epilepsy, to treat other conditions—why are women not being widely warned of its potential dangers? I accept that it is important to control epileptic seizures during pregnancy, but given that anti-epilepsy drugs increase the risk of foetal malformations, delayed development and foetal and maternal death, women with epilepsy are in an impossible position. They must either continue to take the drugs or risk seizures, both of which pose an increased risk to the mother and the foetus. Pregnant women who abandon their medication are at an increased risk of developing uncontrolled seizures, which can be fatal. About four women with epilepsy die during pregnancy each year, but those deaths could possibly be avoided if the right support were provided.

I am sure that we will talk a great deal about numbers and statistics this afternoon, but let me put into context the way in which epilepsy affects people. I know a woman who, at the age of 15, began to have night seizures in her sleep. She was diagnosed with epilepsy and was prescribed sodium valproate. Eleven years later she married, and she and her husband decided that they wanted children. In 2007, having done some research and understanding the risk that sodium valproate would pose to her baby, she changed her drug. There followed, from 2008, a terrifying five years of daytime seizures she had never had to deal with before. Her previous seizures had always taken place while she was asleep, and she had been seizure-free for 12 years.

The woman was now afraid to go out. She was afraid to get on a bus, and she was afraid to go to work. She was a teacher of primary school children, and she was terrified of having a seizure in front of them, because they would not know what to do. But the bitterest pill of all was finding that, either because of the increased seizures or because of the new drugs, she was no longer ovulating. She had to choose between taking a drug that would stop the seizures but might pose a risk to the baby, and taking a different drug, having the seizures and risking her fertility. That is a very difficult position for women to be in, and they need advice.

The Minister of State, Department of Health (Norman Lamb): I take this issue extremely seriously. There has been an EU-wide review of the risks involved. The Medicines and Healthcare Products Regulatory Agency issued new guidance in January, and the British National Formulary has also been updated. The Department is considering the introduction of a “red flag” system to notify GPs of the risks posed to women of child-bearing age, and I personally am very keen to introduce such a system.

Teresa Pearce: I know that the Minister has met some of the mothers involved, and I am very grateful for that. Women such as the one I have just mentioned are in desperate need of specialised guidance and support from their GPs, but there is no such support at present. GPs should be providing pre-conception counselling and tailored advice, but they do not appear to be taking that responsibility seriously. In 2012, a survey by Epilepsy Action revealed that 26% of women who had been pregnant in the last five years, or were planning to become pregnant, had never received counselling. That puts women and unborn babies at risk.

Pre-conception counselling should be fully embedded in the care pathway of all women with epilepsy and child-bearing potential, and there should be a specialist care pathway for all women with epilepsy to ensure that their pregnancies are flagged as potentially high risk. Every such woman should receive regular input from an epilepsy specialist and an obstetrician, and any breakthrough or worsening of seizures should be investigated as a matter of urgency. Will the Minister tell me what funding, training and planning are needed to implement those steps?

The co-operation of GPs and health care professionals is crucial to ensuring that any strategy actually works. I welcomed the stronger guidance that was released in January by the Medicines and Healthcare Products Regulatory Agency. It states that sodium valproate should not be prescribed to female children, female adolescents, women of child-bearing potential or pregnant women unless other treatments are ineffective or not tolerated. As the Minister said, the guidance followed a Europe-wide review. What steps will the Department take to ensure that it is fully implemented? Every woman taking an anticonvulsant has the right to an informed choice, but we know that information on the effects of sodium valproate on pregnancy was withheld from female patients in 1972. Following the European review in 2014, why has providing information to female patients not been made a mandatory action?

At this moment, the picture is bleak. A recent report entitled "Saving Mothers' Lives" highlighted the failure to reduce maternal deaths from epilepsy over the past two years. If women with epilepsy were provided with support and health care tailored to their specific condition, it is likely that the number of maternal deaths would be reduced. The science is available to ensure that women with epilepsy can have successful pregnancies with the right support, but that must be universally available to all women with epilepsy since simple measures can decrease the risks associated with epilepsy in pregnancy. I have worked closely with women whose children have suffered from FACS and families who have been affected by the lack of information.

In particular, I have worked with Janet Williams and Emma Murphy, who run IN-FACT, the Independent Foetal Anti-Convulsant Trust, and I respect and admire them for their relentless commitment and dedication to raising awareness of this issue. I first met them just after I entered the House in 2010, when families were devastated following the withdrawal of legal aid case for a class action against the manufacturers of the drug. After six years of preparation, that trial did not go ahead. I tabled an early-day motion, signed by 82 MPs, urging the Legal Services Commission to reconsider, but it did not. Last year, I wrote to the Department of Health to ask whether compensation would be available. I received a response from the Under-Secretary of State for Health, the hon. Member for Mid Norfolk (George Freeman), who is responsible for life sciences. He said: "Compensation for people who believe they have been adversely affected by a particular drug is a matter for the judicial system".

I also received one from the Minister of State, Department of Health, the right hon. Member for North Norfolk (Norman Lamb), who is responsible for care and support, who said: "it would be inappropriate for ministers to intervene in or comment on matters which must remain for the judicial system."

The fact is that these families have sought justice and done everything they can, but they have been denied support and denied justice. Will the Government act?

Steve Baker (Wycombe) (Con): I ask the Government to take a close interest in the case of my constituent Jessica Monks, which I shall relate from the perspective of her parents. I am grateful to my hon. Friend the Member for South Thanet (Laura Sandys) for creating the opportunity for me to do so and for giving me the opportunity to inform myself about this important issue. I have been astonished by what I have learned.

I am glad to follow the hon. Member for Erith and Thamesmead (Teresa Pearce). As she will learn, I too will talk about issues of consent towards the end of my speech. It was shocking to hear what she set out about consent.

Jessica Monks was not just a cheerful but a positively joyful young woman. Her life and untimely her death are a case study in what can go badly wrong and what ought to be done. Jessica was born on 7 February 1996 and lived in Medmenham in my constituency. She suffered from epilepsy and was under the care of the neurology department of the John Radcliffe hospital in Oxford. I understand that she was learning to live very well with her condition.

Jessica died by suicide on Saturday 24 January 2015 as a result of a psychotic episode related to the epilepsy medication she was taking. She had been taking Zonisamide since about November 2013, but her seizures had not stopped. Her neurologist told her parents to keep an eye on her moods and to make an appointment with him immediately if her moods changed in any way.

Over Christmas 2014, Jessica, usually a joyful young woman, became noticeably low and withdrawn, very unlike her usual buoyant self. As requested, Mr and Mrs Monks attempted to make an

appointment for Jessica to see her neurologist about her changing moods in early January, but despite several phone calls they did not receive a response. Her parents were concerned about her deteriorating mood so they made an appointment with her GP, who saw her on 8 January. The GP agreed that her mood had deteriorated but, crucially, felt that it was important to speak to her neurologist before prescribing any medication to help her mood improve.

On Friday 9 January, Jessica was admitted to Wexham Park hospital after taking an overdose of Zonisamide, oxcarbazepine and paracetamol. She was seen by a junior psychiatric nurse, and I am surprised that it was a nurse. I am sure that they do a wonderful job, but I would have thought that in such circumstances a consultant would have been appropriate. However, the nurse deemed her fit for discharge. Following a further attempted suicide on Monday 12 January, Jessica's parents made another appointment to see her GP who again recommended that Jessica be prescribed an antidepressant but felt unable to do so until she had spoken to her neurologist. The GP did arrange an urgent psychiatric appointment for Jessica and, thankfully, the psychiatrist phoned that evening to make an appointment and offer out-of-hours support.

At the psychiatric appointment on 22 January, Jessica was diagnosed as suffering from a psychotic episode and was instructed to stop taking the anti-depressants immediately. The psychiatrist was concerned that the drug Jessica was taking was causing this psychotic side effect—which is, by the way, well known—and said she would speak to the neurologist that evening to discuss whether Jessica should cease taking the epilepsy drug Zonisamide.

On Saturday 24 January, Jessica died when she stepped in front of an oncoming train.

Norman Lamb: My hon. Friend is talking about a tragic case and I cannot begin to imagine what the family have been through. I am very happy to meet him to discuss further what lessons can be learned.

Steve Baker: I am extremely grateful to my right hon. Friend.

Mr and Mrs Monks feel that there was a significant breakdown in the care of their daughter, and I certainly agree with them. The speed and severity with which her mental health deteriorated due to her epilepsy medication were not considered a priority—they were not adequately prioritised—and they feel they have been badly let down by the medical professionals they saw in the days leading up to Jessica's death.

Jessica's death was apparently avoidable. We need to know why it was not avoided. There are a number of questions to be answered by the NHS and the investigation is ongoing, as, indeed, is the coroner's inquest. I contacted the coroner before raising this case and they were content for me to do so. I will not run through all the questions, some of which are apparent, but I should like to ask in particular why was the consultant neurologist not more available? Why, when it is well known, as the Library brief explains, that some of this medication can cause these side effects, was more immediate, perhaps telephone, support not available in the event of an episode?

Mrs Gillan: Among other things, I sit on the Public Administration Committee and we are responsible for the health ombudsman. Will my hon. Friend make sure that the details of this case are passed to the Committee and to the ombudsman, because we are looking into how complaints are dealt with and how we can learn for the future from such tragic experiences?

Steve Baker: I am extremely grateful to my right hon. Friend. I have already passed the details to the Minister. I am aware of the inquest and the NHS investigation, but I will certainly take her advice and give those other bodies the opportunity to investigate.

That brings me on to the specific issue of consent. I have spoken to Mr and Mrs Monks today and they say that at no point was it explained to them that this medication could have these side effects. Jessica was 17 when she started taking it, and I feel that that possibility really should have been explained to her parents. They should have had the opportunity to take very strong action. Of course, they did take very strong action—they took the strongest action they could—and it seems to me, without wishing to pass judgment, that the key problem was that they could not get hold of the neurologist.

Dr Julian Lewis (New Forest East) (Con): I am puzzled that the instructions that came with the medication did not include a warning that if someone had those sorts of side effects, they should cease taking it.

Steve Baker: I am a layman, but one of the things I have learned today is that one cannot simply cease taking medication for epilepsy, so specialist advice is required.

Laura Sandys *indicated assent.*

Steve Baker: I am grateful to my hon. Friend for acknowledging that. Put simply, it seems that the epilepsy medication, which was necessary, caused psychotic side effects, which were exacerbated by anti-depressants that were prescribed with the best intentions. Jessica therefore spiralled into the situation that tragically led to her death.

I would like to finish with a few words from Jessica's parents, who have written to me:

"The sudden and tragic death of our otherwise healthy and happy teenage daughter has caused devastation throughout our family and local community. We strongly feel that this situation could have been avoided if we were given the correct advice and prompt treatment and are committed to ensuring the same mistake does not happen to another epilepsy patient."

Susan and Steven Monks have been robbed of their daughter and of all the future opportunities, hopes and dreams for which she stood. They deserve to know why and what will be done about it.

Valerie Vaz (Walsall South) (Lab): It is a pleasure to follow the hon. Member for Wycombe (Steve Baker). I am sure I speak on behalf of all hon. Members in asking him to pass on the sympathy of the House to his constituents, whose case he has so ably put forward.

I start by paying tribute to the hon. Member for South Thanet (Laura Sandys) for her work as chair of the all-party parliamentary group on epilepsy, and for fulfilling her final task of securing this debate before leaving the House. She will be sadly missed; we shall also miss her enthusiasm and her commitment to epilepsy and to her constituents, for whom she has been an assiduous MP.

Laura Sandys: I am absolutely thrilled that the all-party group's chairmanship has been handed to my hon. Friend the Member for Walsall South (Valerie Vaz), who I know will put a huge amount of passion and energy into continuing the fight and ensuring that the voice of those with epilepsy is very much heard.

Valerie Vaz: I am grateful to the hon. Lady. I hope to be as good as her, but I am not sure that I will be. This is a timely debate, in that it comes between two important dates. The World Health Organisation adopted a resolution on 2 February this year, and world epilepsy day is on 26 March, when we are all urged to "colour it purple". It is just an accident that I happen to be wearing purple today. This debate is taking place 12 days after 14 February, and most people probably know that St Valentine is the patron saint of epilepsy. The WHO launched a campaign on 9 February to improve the epilepsy treatment gap and it urged member states to look into the matter. It set out a number of clauses, and I shall mention just a few of them. Member states were urged: to ensure public

awareness of and education about epilepsy; to integrate epilepsy management; and to introduce and implement national health care plans of action for epilepsy management. There are many more clauses and I urge hon. Members to look at them. A number of excellent reports have been published recently and I will touch on those in a moment.

I want to deal with three different stages of services: those for young people; the transition from young person to adult; and adult services. Here are some background facts. The brain is the most complex organ in the body with more than 100 billion neurones passing messages around it. The vast majority of the brain's activities are subconscious. Epilepsy is a life-threatening neurological condition that can affect anybody at any age without warning. There are 40 different types of epilepsy and at least 40 different types of seizure, and 87 people are diagnosed with the condition every day. Epilepsy now accounts for more deaths than cervical cancer and is among the top 10 causes of amenable deaths.

I want to turn first to young people. The report "Improving epilepsy care for children and young people", published by Young Epilepsy, University College London and Whittington Health highlighted unacceptable levels of misdiagnosis, inadequate communication, a variation in care and a fragmentation of services. There are 112,000 children and young people who have epilepsy, which is one in every 200. The report made seven recommendations. They include creating an individual plan for every child and young person—as one parent has said, a one-size-fits-all approach is wrong; designing a year-of-care tariff for epilepsies; and creating an audit and annual review of relevant outcomes for each child and young person. Dr Amit Bali, who was involved in producing the report, has said that only small steps have been taken in areas that require big leaps forward.

I was at the launch of Epilepsy12 at the Royal College of Paediatrics and Child Health a few years ago. A number of charities were also involved in that, including Epilepsy Action and Young Epilepsy. Epilepsy12's report revealed variations in the level of care and available resources such as the specialist nurses and clinics that are needed to provide care across the United Kingdom. Amazingly, it also found that some services were not even meeting NICE guidelines. In a later report, published in 2014, Epilepsy12 said that some progress had been made, and that two thirds of units had specialised epilepsy nurses and more clinics were being held. However, only two in every three units reported holding a weekly epilepsy clinic just for children and young people.

The way in which young people are treated is important because it affects their education as well as their lifestyle. A three-year population-based study by Children with Epilepsy in Sussex Schools—CHESS—found that 95% of the children affected had difficulty in at least one of the assessed areas and that most of the children had several problems. The CHESS study found that 60% of the children met the diagnostic criteria for at least one behaviour or motor disorder, but only one third had previously been diagnosed. We have heard about the difficulties that children on anti-epileptic drugs have. A study by the Epilepsy Society showed that AED drugs have a detrimental impact on processing speed and memory work.

On the transition period, Epilepsy12 found that there were inadequate services and transition arrangements for young people. So more attention needs to be given to handover clinics, which could comprise both adult and paediatric health professionals. The loss of the continuity of care at transition needs to be addressed to ensure that new relationships with the clinicians are established.

Let me now discuss adults. The report by Epilepsy Action on clinical commissioning groups and commissioning in November 2014 found that only three out of 140 health and wellbeing boards are making plans for people with epilepsy. Some 78% of CCGs have not developed and do not intend to develop a written needs assessment for people with epilepsy—that must change. Evidence also

shows that people with epilepsy have poor access to epilepsy specialists and epilepsy specialist nurses, and do not have regular reviews of their epilepsy. My hon. Friend the Member for Vauxhall (Kate Hoey) was kind enough to mention my ten-minute rule Bill, in which I called for direct referrals to a tertiary specialist: That has not been taken up yet, so we need to have referrals from a GP specialist to a tertiary specialist without the need to go through a generalist consultant.

The sudden unexpected death in epilepsy is an important issue, as was highlighted by SUDEP Action. The national sentinel audit of epilepsy deaths in 2002 found that 42% of such deaths were potentially avoidable. Brain surgery is another area where there is a lack of availability, with only 300 operations being carried out on adults each year. It is estimated that approximately 5,000 adults could and should benefit from the only cure there is for their epilepsy. I also wish to add my voice to those of other hon. Members on the outrage at the sacking of the young person at London Underground.

But there is hope for the future. The Epilepsy Society is undertaking active research. Its report highlighted a number of firsts, such as the first brain and tissue bank for epilepsy. It has created the first multilingual digital information resources for epilepsy, and it hopes to unravel the genetic architecture of the epilepsies and bring new hope for people with the condition. We should consider ourselves lucky in this country, because not only do we have committed practitioners who are desperate to help their patients, but we have areas where pioneering work is going on, such as that being done by Professor Cross, who has pioneered the ketogenic diet. In the US, until there was “Obamacare” those with epilepsy could not be covered by insurance because they had a pre-existing condition. We take all that for granted, which is why this debate fulfils the important role of highlighting awareness of this condition.

Hon. Members will remember the drama “The Promise”, where the lead character, Erin, not only was a heroine, but had epilepsy, which was incidental to her life: Its writer, Peter Kosminsky, lately the director of “Wolf Hall”, said that he wanted to show someone being brave and getting on with her life without letting her epilepsy circumscribe her actions, in the hope of de-stigmatising the condition. On de-stigmatising, let us also not forget the roll call of creative successful people who have or have had the condition: musicians Neil Young and Prince; and the writers Dostoevsky; Charles Dickens and Lord Byron. I hope we have today brought epilepsy out of the shadows of stigma and discrimination, and into the spotlight of knowledge, awareness and hope for the future.

Several hon. Members *rose*—

Madam Deputy Speaker (Dame Dawn Primarolo): Order. We are running out of time for this debate. I want to be fair to all Members, so I am reducing the time limit to seven minutes. If there are not too many interventions, it will not be necessary to reduce it further.

Greg Mulholland (Leeds North West) (LD): I start by congratulating my hon. Friend the Member for South Thanet (Laura Sandys) and my right hon. Friend the Member for Chesham and Amersham (Mrs Gillan) on securing this important debate and giving us all the opportunity to contribute on behalf of our constituents. I particularly thank my hon. Friend for bringing her experience and for what she has done during her time here, and I echo the sentiment that it is a shame she will not be coming back to carry that on. Other people will have to do that, and I am sure right hon. and hon. Members will do that here.

It is important to start by saying that my right hon. Friend the Minister of State, Department of Health has taken a real interest in epilepsy and that he and his colleagues have introduced significant improvements in this Parliament. Equally, the NHS Commissioning Board’s decision to introduce a

national clinical director for neurological conditions, Dr David Bateman, has been positive in ensuring that epilepsy is on the agenda at the most senior level in the NHS.

In February 2013 we saw the publication of the NICE new quality standards for children and adults with epilepsy. I also welcome cross-departmental working, and the fact that the Department for Education is looking at better support for pupils in school diagnosed with epilepsy. There is still a lot to do, and still too much of a sense that care is good in some areas and poor in others; that has to be a priority for the next Government.

I am proud that Epilepsy Action, an excellent organisation, is based in Leeds. Its headquarters are in Yeadon, an area that I represent. The office is about 100 yards over the border in the constituency of my hon. Friend the Member for Pudsey (Stuart Andrew). We share Yeadon, but we are both proud that this wonderful national charity is based in Yeadon in north Leeds. I will not repeat the findings of its powerful survey, except to reiterate one figure. Of the clinical commissioning groups that responded, 70% said that they had not produced and had no plans to develop a written needs assessment of the health and social care needs for epilepsy. That is simply not good enough and it has to change, and quickly. I urge my hon. Friend the Minister in the time that he has remaining to make it clear that that is not acceptable and must change.

Every health and wellbeing board must know how many people in their area have epilepsy and develop an epilepsy section for their joint strategic needs assessment, and that should include information about current local provision and services and future needs. Health and wellbeing boards must also work with their local CCGs to ensure that adults and children in their area experience a joined-up approach to their epilepsy health care needs. Every local authority scrutiny board with responsibility for health must consider whether their JSNA adequately meets the needs of adults and children with epilepsy in their local area.

I am delighted to tell my right hon. Friend the Minister that the Leeds Teaching Hospitals NHS trust—this is not me saying it, but my constituents and practitioners tell me—is one of the best trusts in the country for supporting those who have epilepsy. We are proud of that. The trust has a team providing specialist epilepsy care and advice for people in Leeds and the wider Yorkshire region, and as well as the medical treatment of epilepsy it runs an epilepsy surgery pathway for people with difficult-to-treat epilepsy. It has specialist brain tumour and vagal nerve stimulation clinics. I hope that my right hon. Friend will join me in recognising that Leeds is a centre of excellence for epilepsy. If, in the remaining five weeks while he is definitely in this particular job he has the time to come and visit to meet some of the people involved, I would find time in my diary to join him.

Like many other Members, I have learned from my constituents about epilepsy. My constituent Dominic Ware and his parents Vic and Carol have given me their permission to pass on some of what I have learned from them. My constituent Andy Cavadino also has epilepsy. They have enabled me to see both the good and the issues that need dealing with.

Andy Cavadino's epilepsy developed over 10 years after a serious head injury. The two main issues affecting him relate to driving and to medication. As a teacher, he finds it frustrating that he is allowed to drive a people carrier but not a minibus. He wants there to be a much more transparent discussion about what vehicles can and should be driven by people with epilepsy. The second issue that he raises has already been covered by other hon. Members. People have an attitude to those with epilepsy; they are often nervous and on edge around people with epilepsy. As Andy told me, people sometimes say, "Take it easy." We need to raise awareness that people with epilepsy are generally on medication, if they need to be, and that that is helpful. We must do more to fight the sense of concern, paranoia and stigma that is attached to people such as Andy.

Dominic Ware's epilepsy has been a huge part of his life and that of his parents, Vic and Carol. It is something that they have to cope with. The care that Dominic has received in Leeds has saved his life and now enables him to lead a normal life, which is precisely what needs to happen. However, they and especially Vic, who is a passionate campaigner, know that for too many people, that is not the case. During the debate, we have heard of people who, unlike Dominic, have been failed, often with devastating effects, and that is simply not acceptable. Will my right hon. Friend the Minister support Vic's call that whoever forms the next Government should appoint an epilepsy champion in the Department of Health to bring things together so that there is a single, strong voice in government to push the issue forward?

Madam Deputy Speaker (Dame Dawn Primarolo): Order.

Mr George Howarth (Knowsley) (Lab): I add my thanks to the hon. Member for South Thanet (Laura Sandys) for giving us the opportunity to debate this important issue. I wholeheartedly endorse hon. Members' comments that she will be missed in the House. Her speech was not only informative but unique, because in the many years I have been in the House, I have never before heard a Member declare themselves to be both a law-maker and a law-breaker. Even more alarmingly, she declared her intention to become a repeat offender. Her speech was also unique in that it brought before the House the experience of people who suffer this condition, and she gave us the opportunity to understand more about its dimensions.

I need to say a word about the speech made by the hon. Member for Wycombe (Steve Baker), in which he described a tragic case. Anyone who has experienced the loss of a child knows exactly the depths of misery that the people concerned will have experienced. The hon. Gentleman dealt with a difficult subject in not only a suitably moving way, but with great dignity, and I, too, pass on my sincere condolences to the family.

Steve Baker: I am extremely grateful for the right hon. Gentleman's kind words. I know that the family have heard him and will also be grateful.

Mr Howarth: The hon. Gentleman's speech highlighted a more general point about how chronic conditions are dealt with. I have some knowledge of type 1 diabetes. When someone with that condition reaches a crisis, whether that is a psychological crisis or something that should be dealt with by a diabetologist, they cannot always get to see the right people at the right time so that they can get the right support, prescription or advice. Brilliant though our national health service is, that is one aspect that all too often breaks down, so I hope that the Minister will address that problem.

I want to concentrate on a particular issue, which I do not think has been mentioned, about which one of my constituents has contacted me: how the benefits system makes life very difficult indeed for those people who find themselves on benefits. No doubt the Minister will not be able to respond to my points, but I hope that he will pass them on to his colleagues in the relevant Department.

My constituent, who has asked to be named, Mr Adam Lane, who lives in Huyton, said:

"In regard to my DLA claim I had to go through 6 months with no money for myself, my wife and my two-year-old son. At that time we had to live on £50 a week until I went to a tribunal and won. Now I have to go through the whole process again on 13th of March for PIP. I have a letter from my epilepsy doctor stating how bad my epilepsy is. I fall and convulse without warning and have seriously damaged my knee, and have panic attacks throughout the whole experience. My seizures are occurring every week now and are very serious and now I suffer with migraines where I vomit 14 hours a day and I'm confined to bed through the process for 2 weeks at a time. I'm hoping Atos will not brush me off like last time, hoping to appease Government numbers to get people off benefits. I

feel I am in need of benefits. I cannot work with my health conditions. My wife is my carer 24/7. My son has been traumatised though watching my seizures. I'm hoping my Atos interviewer sees what is in front of their eyes and not what the Government want them to see and say. Please, for others out there like me, let there be a way for people who do not abuse the system to be given a fairer crack of claiming what is deservedly theirs. Thank you."

I thought it was worth reading that out in full because it gives a very clear picture of how this man has had to struggle to keep his family together and to support them in extremely difficult circumstances, where the benefits system seems to mount up against him to prevent him having any kind of reasonable life. I hope that such cases—there are many more of them out there—give the Government cause to think again about how people with chronic conditions are dealt with in the benefits system.

Sir David Amess (Southend West) (Con): The whole House was moved by the speech of my hon. Friend the Member for Wycombe (Steve Baker). The pain of losing a child under such circumstances is unimaginable.

My hon. Friend the Member for South Thanet (Laura Sandys) started her speech by beating herself up because she did not feel that she had done enough to raise the profile of epilepsy. Nothing could be further from the truth. She has done a magnificent job, and she made my day with her invitation to colleagues to come up with ideas about how she should break the law as an epileptic. When she gets back to her room later, she will find that she is inundated with suggestions. I, like others, am very sorry that she has chosen not to stand in the next election. I hope to God that she is replaced by someone with the good common sense and judgment that she has shown throughout her time as a Member.

Epilepsy is a potentially life-threatening neurological condition, as other speakers have said. It affects the lives of nearly 500,000 people in England alone. It can reduce life expectancy by up to 10 years and can leave people unfit to work, as we have heard. Among other consequences, epilepsy affects children's performance at school owing to seizures. Nearly half of the number of deaths from epilepsy can be avoided. In the constituency that I represent, there are an estimated 865 people suffering from epilepsy. This figure increases to 13,600 for the county of Essex.

What are the local CCGs doing to assist people with epilepsy in the area that I represent? I am afraid to tell the House that the answer is not enough. Clinical commissioning groups have a very important role to play. They have a strategic influence and make commissioning decisions that impact on the lives of an average of 2,370 epilepsy sufferers in each CCG area. I have recently been in contact with Epilepsy Action which—I agree with others—is doing a wonderful job in raising awareness of the problems faced by people with epilepsy. I was shocked to hear that my local Southend CCG has no plans to produce a written needs assessment of the health and social care needs of people with neurological conditions; has no plans to produce a written needs assessment of the health and social care needs of people with epilepsy; has not identified neurology or epilepsy as an improvement and saving opportunity; has not identified neurology as a priority for the local health and wellbeing board; and has not appointed a clinical lead for neurology. That is simply not good enough.

Southend West has a higher than average number of people with epilepsy, because of its high age profile. The correct ratio for specialised epilepsy nurses to patients is 1:300. The specialist nurse at Southend hospital is currently looking after more than 1,000 patients, which is absolutely ridiculous. That has to change. More specialist epilepsy nurse posts must be created before any improvements can be felt by my local residents. I fully accept that it is a country-wide problem, but it is very frustrating that most CCGs do not understand the needs of people with epilepsy.

I am in regular contact with the South East Essex Epilepsy Support Group, which is superbly led by its chairman, Mrs Diane Blake-Lawson. It is a wonderful source of information and support for epilepsy sufferers in the area I represent. I hear about all sorts of obstacles faced by people with epilepsy. Very often local residents are diagnosed and then they and their families are left without any medical guidance or support, and we heard a little about that earlier. I was particularly upset to hear that Southend hospital has on a number of occasions refused MRI scans and other medical examinations.

I have received complaints regarding the prescription of generic drugs, despite evidence suggesting that their use leads to an increased risk of seizures. Even more alarmingly, I was informed that the latest drugs are not made available to patients, as older and less effective drugs are cheaper to use. That is just not acceptable. Local residents often get caught up in a confusing situation where the hospital says that they should speak to their GPs first, but once they contact their GPs there seems to be a reluctance to give any advice and they are told to turn to neurologists instead. There is clearly a lack of GP training in epilepsy.

Nationally, only 20% of people with epilepsy who are referred to see a specialist are seen within the NICE-recommended waiting time. Even worse, there is an 18% gap in the treatment of epilepsy, meaning that 18% of people with epilepsy who could attain seizure-freedom experience seizures unnecessarily due to a lack of appropriate treatment.

I want to touch on the issue of benefits, which the right hon. Member for Knowsley (Mr Howarth) also raised, because a number of people are adversely affected by the present situation. As we all know, the process of claiming benefits can be lengthy and stressful, which in turn can aggravate the psychological symptoms as well as the frequency and severity of seizures. What I am most concerned about is the ability of benefit medical assessors—they are rarely doctors—to recognise and appreciate the severity of epilepsy.

In conclusion, I think that there is a role for the Government to play. We need more funds to be invested in medical research to ensure that more people with epilepsy can access effective treatments. Southend residents suffering from epilepsy should not be denied access to the various treatment I mentioned earlier. For too long epilepsy has been forgotten when it comes to funding and the variety of treatments available. It is time for the Government to hold CCGs to account to ensure that due gravity is given to this very serious condition. As my hon. Friend the Member for South Thanet passes the baton to the hon. Member for Walsall South (Valerie Vaz), I hope that in the next Parliament, whoever forms the next Government, we will do our very best to provide the best possible treatment for those who suffer from epilepsy.

Grahame M. Morris (Easington) (Lab): I, too, congratulate the hon. Member for South Thanet (Laura Sandys) and the right hon. Member for Chesham and Amersham (Mrs Gillan) on securing this important debate. In common with many other Members, I would like personally to thank the hon. Member for South Thanet for the excellent work she has done. She might not thank me for a glowing tribute, given that I am on the left of the party, but I think that she is a thoroughly decent MP who does an excellent job. She will be sadly missed. I am perhaps a less active member of the all-party group on epilepsy, but I am a member of many other all-party groups, particularly those on health and cancer. This is a very timely debate. It is thanks once again to the Backbench Business Committee that we have been afforded this opportunity to raise awareness of this important and often misunderstood condition.

In a previous role—I was not double-jobbing, I might add—I worked in the national health service in an analytical chemistry lab where I used to do tests on anti-epileptic drugs using gas chromatography techniques, so I know a little bit about the chemistry but not so much about the clinical manifestations and symptoms. I pay tribute to the tremendous and powerful speech by the hon. Member for Wycombe (Steve Baker), which really brought home the potential risks of this condition if left unregulated. It is one of the most common neurological conditions in the United Kingdom. As the hon. Member for South Thanet said, 500,000 people in the UK, or one in 100, have the condition. That is a considerable number of people. As I think we are all aware by now, epilepsy is not one condition but a composite. Other Members have mentioned the suspected link with autism. There are about 40 different types of seizure and perhaps as many as 50 different syndromes with various degrees of severity and complexity. However, with the right treatment, the right medication and the right support, there is no reason why someone suffering from epilepsy cannot lead a full and active life, as the hon. Lady so ably explained.

Many Members have talked about access to medical care and stigma, but I want to stress another aspect—the discrimination that can be faced by those with epilepsy, creating barriers to education, and, more particularly, to employment. A report published by Young Epilepsy found that three quarters of people with epilepsy have experienced discrimination due to their condition. This situation was reaffirmed by work commissioned by the disabilities charity, Quarriers, which found that more than two thirds of people with epilepsy admit that they worry what members of the public would say or do if they had a seizure, with over a third expressing concern that having a seizure in public has led to anxiety about whether to leave the house, even, let alone take up employment. In relation to employment, more than seven in 10—72%—stated that their condition had an impact on their career progression and choice, with more than two fifths avoiding even telling people about their epilepsy.

There are protections in place for those looking for work and for those who are in work, but I am concerned that these duties and obligations are not being met by employers. Equality laws make it illegal for employers to treat people with epilepsy unfairly, and protection must be provided against bullying and harassment due to their condition. Employers also have a duty to make reasonable adjustments to help people with epilepsy to get into work, or stay there, and to prevent them from being at a substantial disadvantage. However, we have found that people with epilepsy have been shown to be twice as likely to be at risk of unemployment as those without the condition.

The case of Karen Guyott, which was mentioned by my hon. Friend the Member for Vauxhall (Kate Hoey), has been drawn to my attention before. To comply with the instructions from yesterday, I am, as it says in my entry on page 205 of the Register of Members' Financial Interests, a member of the RMT parliamentary group, although it is unremunerated and the RMT is not affiliated to my party. It is important that we speak in this House on behalf of working people, and charities, and raise legitimate concerns. That example of someone losing her job is an important test case because, as my hon. Friend said, London Underground did not provide the training or support required.

I only have a little time left, so I want to put this to the Minister, who I know is a decent and reasonable man: at the conclusion of the debate, I hope that he will make it clear that it is unacceptable to discriminate against someone due to their having epilepsy. I hope that he will support people, such as Karen, who are fighting blatant discrimination. Will he agree to raise her case with the Mayor, because Transport for London comes under the Mayor's auspices? TfL is a significant public sector employer, and we want it to be an example of best practice. Will the Minister meet a delegation of interested MPs to discuss discrimination and epilepsy at work?

Martin Horwood (Cheltenham) (LD): I commend the hon. Members who secured this debate, and the Backbench Business Committee for bringing this very serious issue to our attention. I have found the debate genuinely shocking.

The statistics are shocking enough: 600,000 people in this country have epilepsy. That puts it on the same scale as dementia and Alzheimer's disease, but it receives far less attention, perhaps because we feel that we are used to epilepsy and it is not that serious. Another shocking statistic is that 1,000 people a year die of epilepsy-related deaths, and most shockingly of all—this was mentioned by the hon. Member for Walsall South (Valerie Vaz)—42% of those deaths are preventable, in many cases with little more than good communication.

The debate is all the more shocking and upsetting for me because of the case of Emily Sumaria. Emily went to my junior school in Cheltenham, and attended the secondary school of the right hon. Member for Chesham and Amersham (Mrs Gillan), Cheltenham Ladies college. From there, she did work experience in Parliament with me for several weeks. I remember her as a brilliant young woman who had the kind of smile that lights up a room. Her mum, Rachel, describes her as “a bright, beautiful and funny girl with her whole life ahead of her. Her epilepsy was totally under control and she lived a perfectly normal life.”

Indeed, I had no idea she was epileptic. She went on to get four good A-levels and then started at Leeds university, but she never graduated.

On 4 December 2012, Emily was found dead in her bed by her university housemates. Her mum says: “Neither she nor I were ever told about the possibility of dying and had never heard of SUDEP”—sudden unexpected death in epilepsy. The explanation was tragically simple: Emily's university GP practice prescribed the wrong dosage of her medication when she moved from her home GP, which meant that when she missed one day of her tablets, she did not have enough in her bloodstream to prevent her from having a seizure. That one and only seizure, after almost two years, killed her. Rachel says: “Knowledge is power and maybe if Emily or I had known about SUDEP then we could have taken additional steps to minimise her risk. This totally avoidable death has had devastating effects on a huge number of people. The ripple effect of Emily's death has been enormous.”

SUDEP Action, the charity which looks into sudden unexpected death in epilepsy, states that being “open and honest with patients about their level of risk, allows them to make educated choices as to their ongoing care and management”, but that GPs in primary care lack confidence with epilepsy, and that even specialist services “do not routinely discuss” with patients the level of risk and much more serious risks of which some of them may not be aware. One of the families who contacted SUDEP Action said: “There is nothing worse than losing a child but to feel that [our son] did not have all the information he needed to make informed decisions makes it especially cruel.”

There is also an issue about information for bereaved families after death has, tragically, occurred. NICE guidelines state: “Where families and/or carers have been affected by SUDEP, healthcare professionals should contact families and/or carers to offer their condolences, invite them to discuss the death, and offer referral to bereavement counselling and a SUDEP support group.”

Yet SUDEP Action says that that is not happening. It is aware of many people bereaved by epilepsy who find no specialist support and who are often left struggling to understand what has happened to them and why.

In 2013, SUDEP Action launched—with, I am pleased to say, Government support—the epilepsy deaths register. It is not only an amazing research resource, but of enormous value to families, which

the Government should be congratulated on supporting. It offers a means for bereaved families to express what has happened to them. SUDEP Action says: "The bereaved families are robbed of the chance of saying goodbye; of saying the things that they always wanted to, and didn't. They are robbed of opportunities, future hopes and dreams."

The register is therefore an important outlet for the families:

"It is somewhere to leave their story; a way to feel that the information they give will be used for the benefit of others for years to come. The impact of these deaths is not yet fully understood, but in our experience is captured by one of the families reporting to SUDEP Action's Epilepsy Deaths Register: 'The physical pain and guilt are overwhelming, and we are only just becoming able to talk about him to each other after 16 months has passed. The impact is total and devastating, and has affected both the physical and mental health of the whole family.'"

SUDEP Action and families such as Emily's are calling for better information. That means better information at primary care level. I know that this is a constant theme with GPs and that they cannot be experts in everything, but it is particularly important in the case of epilepsy because people do not understand the potential seriousness of the condition. There must also be better communication about risk that is communicated properly by specialist services and better information after death for bereaved families.

We as policy makers have little power to offer much comfort to families such as Emily's, but if we can take action that saves even one more life from sudden unexpected death in epilepsy, it would matter a great deal to Emily's family and friends, among whom I feel proud to have briefly counted myself.

Andrew Gwynne (Denton and Reddish) (Lab): I, too, congratulate the hon. Member for South Thanet (Laura Sandys) on securing this debate. I pay tribute to her outstanding work to advance the cause of those who suffer from epilepsy. She will certainly be missed from this place.

There have been 11 Back-Bench contributions to this debate. I thank my hon. Friends the Members for Vauxhall (Kate Hoey), for Erith and Thamesmead (Teresa Pearce) and for Walsall South (Valerie Vaz), my right hon. Friend the Member for Knowsley (Mr Howarth), my hon. Friend the Member for Easington (Grahame M. Morris), the right hon. Member for Chesham and Amersham (Mrs Gillan) and the hon. Members for Wycombe (Steve Baker), for Leeds North West (Greg Mulholland), for Southend West (Sir David Amess) and for Cheltenham (Martin Horwood) for their considered contributions.

Advocates such as the hon. Member for South Thanet and the others who have spoken today are crucial because of the stigma around epilepsy, which is almost unique. Epilepsy is portrayed on television as somebody falling to the ground and foaming at the mouth, as we have heard in this debate, with the treatment invariably involving an ambulance with flashing blue lights. Somebody with epilepsy may suffer a seizure only once or twice a year, if that, but will live with the stigma of epilepsy all year round. Sufferers would probably prefer to focus on talking and on tackling the stigma.

I find appalling and completely discriminatory the case that was raised by my hon. Friends the Members for Vauxhall and for Easington of the Transport for London employee who was sacked. I hope that action can be taken to rectify that situation.

I, too, looked online at Epilepsy Action's very useful tool. I found that my local clinical commissioning groups, Tameside and Glossop CCG and Stockport CCG, had not produced a written needs assessment for people with epilepsy, or appointed a clinical lead for epilepsy to take charge. That

point was made eloquently by my hon. Friend the Member for Walsall South, the hon. Member for Southend West and others. I ask the Minister to consider how we can ensure that CCGs undertake adequate needs assessments of people with epilepsy. It is increasingly important that local plans are drawn up for local provision.

It is important to recognise that epilepsy care has moved from predominantly secondary care to being based more and more in primary care. That has positives and negatives. Clearly primary care is more accessible, and therefore easier to access on a regular basis, but on the other hand it is less specialist. Some professionals operating in primary care might not have the expertise needed to recognise things that would be significant to a specialist. Some things can be done only in secondary care, as we heard from the hon. Member for Wycombe.

I particularly want to press the Minister on the issue of brain surgery. It is estimated that about 5,000 adults could and should benefit from brain surgery, which is the only cure for epilepsy. To put that in context, only about 3,000 adults have that life-changing surgery each year, so there is clearly more that can be done. Are there any plans to direct NHS England to increase the number of operations undertaken, to produce an adult epilepsy service similar to the one that, to be fair, has been created for children's epilepsy?

According to Epilepsy Action, there are about 30,000 accident and emergency attendances due to epilepsy each year. According to the national audit of seizure management in hospitals in 2014, 18,000 of those could be prevented by the implementation of a better care pathway for people with epilepsy. What is being done to ensure that all A and E departments have a clear referral pathway for patients presenting with a suspected seizure?

There is a clearly a welcome focus on research and development in policy terms. The 100,000 Genomes Project is a good example of the potential for genetics research to change lives. It would be nice to see the project encompass more specialist research into epilepsy, because genetics research could have an untold impact on epilepsy treatment.

A number of Members, most recently the hon. Member for Cheltenham, mentioned SUDEP. This week I, too, heard from the family of Emily Sumaria, who are in Westminster today. As we have heard, Emily died in her sleep while at university. She was bright and funny, with a lifetime ahead of her. Her epilepsy was to all intents and purposes under control, and she lived a relatively normal life. Emily was never told of the risk of sudden unexpected death in epilepsy, which primarily affects young people. The worst that she feared would happen if she had a seizure was that she would have her driving licence removed. Her mother is certain that if she had been told of the risk, she could have taken the necessary precautions and made the necessary adjustments to her lifestyle.

Emily was simply given a regular prescription, and basic mistakes in the moving of her medical records from her home GP practice to her new one at university resulted in her new doctor halving her dose without her knowledge. In preparing for the debate, I found that some medical schools do not include SUDEP in their curriculum in any great detail. It is asking a bit much for young people to research the risks of SUDEP and precautions against it, given that their doctors will themselves often not be fully aware of the details. I suspect that the inclusion of SUDEP, epilepsy deaths and epilepsy risks in the programme at medical schools would help to change that. Perhaps the Minister will give his thoughts on whether that could be brought to the attention of medical schools.

The Opposition have said that we will give every patient full ownership of their medical data; they would be able to share the data with whichever organisations they saw fit. We hope that with more people taking control of their data, we will be able to establish more data-driven research projects. I

doubt that a patient suffering from epilepsy would object to their data being used to develop a cure, but the point is that they would have to give consent for the data to be used in that manner. Data would be more free and research would be immeasurably improved, but the final say would go to the patient.

Let me finish on a positive note, because I am optimistic about the future. Epilepsy research is going from strength to strength, and we are making improvements in treatment, with pharmaceuticals and surgery providing hopeful prospects of a cure. I looked at the NHS Choices website before this debate, and 17 clinical trials are recruiting now in the UK with the aim of advancing our knowledge about the condition. I thank hon. Members who have contributed to the debate, especially the hon. Member for South Thanet whom I wish well for the future.

The Minister of State, Department of Health (Norman Lamb): I congratulate my hon. Friend the Member for South Thanet (Laura Sandys) who has worked with my right hon. Friend the Member for Chesham and Amersham (Mrs Gillan). Together they present a powerful case, and I join everyone in thanking my hon. Friend the Member for South Thanet for everything she has done in this Parliament. She will be very much missed, and her case today was all the more powerful because she has epilepsy and can speak with authenticity. What she said about stigma is right—I see it often in mental health, and it is exactly the same issue in this debate. The fact that not long ago someone with epilepsy could not marry is an extraordinary reminder of what we have been up against. This debate is timely and gives everyone the chance to focus on the condition and on how we can improve the lives of those who have epilepsy. I am pleased that the baton will be passed to the hon. Member for Walsall South (Valerie Vaz), who I am sure will ably continue to articulate the case for people who suffer from epilepsy.

The debate has been marked by reference to two tragedies involving young people, and my hon. Friends the Members for Wycombe (Steve Baker) and for Cheltenham (Martin Horwood) spoke incredibly movingly about the dreadful cases involving Jessica and Emily. We will all agree that we owe it to those two girls to do everything we can to improve the experience of people with epilepsy, and to avoid tragedies of that sort happening. It is important to raise awareness, not only among the public but among clinicians, of the condition and how best to respond to it.

I pay tribute to the work of organisations involved in campaigning and research into epilepsy. The Epilepsy Society is based in the constituency of my right hon. Friend the Member for Chesham and Amersham, and Epilepsy Action in Leeds is close to the constituency of my hon. Friend the Member for Leeds North West (Greg Mulholland). Young Epilepsy has also been mentioned, as has the important work done by SUDEP Action. I remember meeting its members when they were establishing the register, and, as my hon. Friend the Member for Cheltenham made clear, it has the potential to provide incredibly rich data and evidence to help us understand why sudden unexpected deaths occur, and how we can prevent them from occurring in the future. All those organisations are doing incredibly important work.

The hon. Members for Vauxhall (Kate Hoey) and for Easington (Grahame M. Morris) mentioned discrimination. They will understand that I cannot comment on an individual case—I am an ex-lawyer and cautious about these things—but the important point about combating disability discrimination, including for epilepsy, cannot be overstated. Where there has been discrimination, it is incredibly important that there are consequences and that lessons are learned to avoid such things happening in the future.

I cannot begin to do justice to all the important points raised in this debate, so I undertake to write to all hon. Members who have taken part and to respond on important points such as co-

commissioning laser ablation treatment, which was mentioned by my right hon. Friend the Member for Chesham and Amersham, as well as many other issues.

Kate Hoey: When he leaves the Chamber today, will the Minister or one of his staff at least make a telephone call to get some more information about this young woman and London Underground's behaviour?

Norman Lamb: I am certainly happy to explore that, although the hon. Lady will understand why I cannot get involved in the case.

The Government are committed to securing high-quality outcomes for people in England living with epilepsy, whose number is currently estimated at more than 450,000. There are many different types of epilepsy seizure, and although some patients have the condition from birth, others become epileptic later in life. For the majority of people with epilepsy, the condition can be well managed—my hon. Friend the Member for Leeds North West talked about the experience of people in Leeds and the excellent care provided by hospitals there—and they can lead independent and healthy lives. As such, the provision of services for these patients is the responsibility of local commissioners, who are best placed to manage services for local populations. It is critical, however, that those who require more specialised care can access the right services and treatments, which is why NHS England commissions such services nationally. That need not be undermined by co-commissioning with local areas.

The Government recognise the importance of ensuring that patients with suspected epilepsy are diagnosed swiftly and accurately. As most people will be aware, seizures are the main symptom of the condition, and it is common practice for anyone who has experienced such seizures to be referred for assessment by a specialist. Neurological conditions such as epilepsy are part of the generalist undergraduate medical curriculum and a component of GP training. As such, GPs should be able to manage, monitor and appropriately refer the epileptic patients in their care. In secondary care, there are nearly 2,000 full-time equivalent neurologists, and for 2015-16 Health Education England has made a commitment to invest in 217 neurological specialty training places. In addition, specialist epilepsy nurses should be a key element of both routine and specialist neurological care, as set out by NICE and NHS England respectively. I know that my hon. Friend the Member for Southend West (Sir David Amess) has concerns in his locality, but it ought to be part of the picture in each area.

To support clinicians in the management of this condition, NICE has published a guideline setting out best practice on the diagnosis, treatment and care of patients. The guideline recommends that referrals for patients with suspected epilepsy are urgent, with patients being seen within two weeks, if possible. I think that the hon. Member for Vauxhall mentioned a wait of two months. That is not acceptable and should not happen, and the local organisations responsible for the delays should be held to account. If it is possible in other areas of the country, it ought to be possible everywhere.

In addition, if seizures are not controlled or diagnosis is uncertain, people should be referred to a specialist service within four weeks. Most people with epilepsy can have their condition successfully controlled with anti-epileptic drugs, and there are more than 25 types of drugs with which to achieve seizure control. The NICE guideline makes it clear that treatment should be individualised according to the seizure type, epilepsy syndrome, co-medication and life style. On the point made by the hon. Member for Erith and Thamesmead (Teresa Pearce), women with epilepsy wanting to conceive must—absolutely must—be given accurate information and counselling about medication such as sodium valproate. That is critical. I mentioned that the Department was considering the possibility of a red flag system, and I hope it will be possible to achieve that.

For some people with more complex conditions whose epilepsy is more difficult to control, other procedures, such as surgery or vagus nerve stimulation, might be appropriate. Patients whose epilepsy is particularly difficult to treat may be referred to a specialist neurological care provider. In particular, children with epilepsy should be considered for specialised care at an early stage, because of the developmental, behavioural or psychological effects associated with suffering from continuing seizures.

In conclusion, this has been an incredibly important debate, and I will do everything I can to follow up all the important points raised.

Laura Sandys: I want to thank everybody here and to ask the Minister to do something for everybody, not least the two young ladies we have heard about today. Their legacy is worth his doing three things.

The first is to talk to NHS England and work out a pathway to reduce by 400 the unnecessary deaths caused by SUDEP each year. The second is to kick and beat the more than 90% of CCGs that do not have a pathway. That is not acceptable; it is absolutely letting down many people throughout the country. The third is to determine how best to implement the NICE guidelines and ensure that the pathway of long-term chronic care—