# Meeting

Children with Type 2 diabetes

Thursday, 16th May 2019

Committee Room 8, Houses of Parliament

2:15 – 4:00pm

The number of children and young people with Type 2 diabetes is rising. This is not surprising, considering the prevalence of overweight and obesity in children is rising. About 22% of children in reception are overweight or obese, rising to 34% in year 6, especially among children living in deprived areas.

Type 2 diabetes can lead to devastating complications in adults, like heart disease, kidney failure and blindness and it seems to be even more aggressive in children, who develop high blood pressure and high cholesterol even quicker.

Despite this, there are challenges around the diagnosis, management and monitoring of Type 2 diabetes in children. Only 16.7% of young people aged 12 and above with Type 2 diabetes received all key care processes, with 5.4% already diagnosed with eye disease.

It is already shocking that children are having to struggle with a condition that could have been prevented. We need to do more to prevent them from also suffering complications they will have to carry for the rest of their lives.

- What is the safest and most effective way to treat Type 2 diabetes in children, and where should they be treated?
- What is the role of Government and local Government in tackling childhood obesity and preventing Type 2 diabetes in children?

It is important to remember that Type 2 diabetes is still extremely rare in children, with most children with diabetes having Type 1 diabetes, which is not linked to lifestyle and cannot yet be prevented.

The meeting was chaired by The Rt Hon Keith Vaz MP, Chair of the APPG for Diabetes.

After speeches, the Chair opened the discussion to the audience.

## Minutes

The Rt Hon Keith Vaz MP started the meeting explaining how we discuss diabetes in adults at length, but we seldom talk about its impact on children. "The number of children with Type 2 diabetes is rising, and we need to address the issue of obesity. What is the safest way to treat children with Type 2 diabetes? And how do Government and society can prevent it?"

### Speech: Libby Dowling, Senior Clinical Advisor at Diabetes UK

Nearly 7,000 children and young people under the age of 25 have Type 2 in England and Wales. These are figures released November 2018 following reanalysing the data from both NPDA and NDA. Why is this a worry? Type 2 is much more aggressive in children and young people than in adults, with a higher overall risk of complications that tend to appear much earlier.

The 2019 National Paediatric Diabetes Audit revealed:

- Only a quarter of children with Type 2 diabetes aged 12 and above received all key health checks, a completion rate half that of those with Type 1. These checks are for the complications of diabetes. It's of particular concern that so few children with Type 2 get these checks because they have higher risk of complications and the complications appear much earlier.
- Black African and Black Caribbean children have poorer HbA1c than other ethnic groups.
- 22% of children with Type 2 have early signs of kidney disease (albuminuria), twice the rate observed in those with Type 1 diabetes.
- 45% have high blood pressure – risk for cardio-vascular disease.
- 34% have high blood cholesterol – risk for cardio-vascular disease.
- 30.2% children and young people with Type 2 diabetes assessed as requiring additional psychological support.

Children with Type 2 commonly:

- Have family history of Type 2 diabetes.
- Are of Black African/Black Caribbean/South Asian heritage.
- Are from more deprived backgrounds.
- Are overweight or obese.

With more than a third of children in England (34 per cent) overweight or obese by the time they leave primary school, thousands more could be diagnosed with Type 2 diabetes in the next few years.

What needs to happen? Broadly 2 things: prevent further cases of Type 2 in children and look after those who already have it better.

Preventing Type 2 in Children

Everyone wants to be healthy and for their children to be healthy, but it is hard when we are being surrounded by unhealthy food options, lead sedentary lives and when we are bombarded by junk food advertising and supermarket promotions. So, we need to create a society where the healthy choice is the easier choice, and support people to make changes that could reduce theirs and their children's risk of Type 2 diabetes.

We welcome the action the Government and food and drink industry are taking to reduce the sugar in food and drink, including the introduction of the Soft Drinks Industry Levy. We welcome the proposals for clear, consistent and compulsory labelling in the Childhood Obesity Plan published last June. But this is the first step and we need the Government to act on the measures laid out in the plan, particularly:

- Ban junk food advertising on TV before 9pm.
- Restrict supermarket price promotions for unhealthy foods.
- Reduce portion sizes.
- Protect children from adverts for foods that are high in fat, salt and sugar.
- Restrictions of price promotions of unhealthy food.
- Further roll out food labelling so that people know what is in their food wherever they are buying and eating food out of the home.

Looking after children who already have Type 2 better

Type 2 is much more aggressive in children than in adults, with a higher overall risk of complications that tend to appear much earlier. If we don't look after Type 2 better, these children will go on to develop kidney failure, cardiovascular disease and amputations in their 30s and 40s.

This will have a devastating impact on their quality of life and will be a massive cost the NHS. Already 10% of the NHS budget (£10bn) is spent on diabetes, and about 80% of that is on managing complications.

The main problems are:

- We don't know how best to treat it.
- The vast majority of drugs used for Type 2 in adults aren't licensed for children. Some paediatricians use them off label, some don't.
- The criteria to get on a drug trail are very narrow, so many children don't meet them. So it's difficult to get the evidence base we need.
- NICE guidelines for treating Type 2 are very limited (NICE review just consulted on – hoping they will review this).
- Weight loss programmes are unappealing/difficult to get on to/sometimes non-existent.
- Children with Type 2 are notoriously difficult to engage with.

So we need to:

- Prioritise research into safety, effectiveness and acceptability of drugs to treat Type 2 diabetes in children. Consider widening acceptance criteria to allow greater participation?
- Children and young people with Type 2 diabetes should have access to expert treatment by healthcare professionals trained to manage and research the condition and the challenges it presents.
- Consider whether we should treat Type 2 diabetes in specialist paediatric diabetes centres, rather than part of a general paediatric diabetes caseload. Advantages of this include a concentration of patients allowing expertise to develop, expert clinicians readily available, and better access to trials. Disadvantages include families may be unable/unwilling to travel long distance particularly if they have limited income, other family pressures or do not fully appreciate the serious nature of the condition.
- Services for children and young people with Type 2 diabetes should work closely with adult services in secondary or primary care in order to share expertise and enhance transition.
- Have stronger guidance from NICE. More in line with ISPAD and ADA.
- Diabetes UK are about to start work with the RCPCH to engage with children and get directly from them what they want and need to manage their Type 2.

In conclusion, Type 2 in children is a serious condition. It is harder to manage than Type 2 in adults. Children will get complications sooner and will die earlier. It's not their fault or their parents or anyone's. It's time to do something about it now, this can't wait.

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**Keith Vaz MP** asked **Libby Downling** where children get diagnosed with Type 2 diabetes. **Libby** responded that it varies. "You have health checks at school, you would find that you're overweight, and depending on where you live different things might happen. You might get a referral, you might not. It is not consistent across the country."

## Speech: Dr Timothy Barrett, University of Birmingham

I am a consultant in children's diabetes at Birmingham Children's Hospital, and researcher at Birmingham University. I look after children and young people with type 2 diabetes, running a fortnightly clinic. My research has been in describing the pattern of type 2 diabetes in children and young people, and clinical trials of new treatments.

How common is it and is it increasing? We have shown through 2 surveys of the British Paediatric Surveillance Unit that the number of children with Type 2 diabetes has increased by about 30% in the last 10 years. While thankfully, type 2 diabetes affects few children, it makes up about 25% of all new presentations of diabetes in the 20-29 year old age group.

Which children get type 2 diabetes? I and colleagues described the first children diagnosed with type 2 diabetes, at City Hospital, Birmingham, in 2000. I then went on to do a national case finding survey of 200 affected children in 2012. Less than half affected children are white, as it disproportionately affects children from ethnic minority backgrounds, particularly South Asian, children from the Middle East, and black children. It also disproportionately affects children from socio-economically deprived areas. Almost all affected children are overweight or obese, which has led some people to blame their parents for giving them the wrong foods. However the situation is more complex than that: the affected children that I see have a strong family history of type 2 diabetes in their parents and grandparents, suggesting an increased genetic risk. In addition, white children seem to tolerate much greater levels of obesity without getting diabetes, than South Asian children.

Is it a problem? We have many families where they do not see type 2 diabetes as a serious condition, as many family members have it, and it does not always need insulin injections. However, for these children, diabetes is probably for life, we have no cure. These children will be developing complications at the prime time of their lives, when they should be having families and being economically productive.

Is type 2 diabetes different in children compared with type 2 diabetes in adults? This is a more aggressive disease in children, with the insulin secreting cells in the pancreas failing faster than in adults. The National Paediatric Diabetes Audit shows that about a third of children already have high blood pressure, about a fifth have protein in their urine, and at least 1 in 10 have fatty liver disease. Data from registry studies show that the younger people are when diagnosed, the higher their risk for major cardiovascular disease and strokes.

What can we do about it? The first line of management is to help change lifestyle, i.e. exercise and diet. The children with whom I have seen most success, are those where their whole family changed their lifestyle. The national exercise guidelines are for children to do at least an hour a day of exercise that makes them out of breath. This can be moderately fast walking, housework, dancing, exercise bike. Diet recommendations are to cut out takeaway meals, glucose containing fizzy drinks, snacks, and reduce portion sizes. Medicines work but these are designed for adults and are unpalatable (metformin comes in big tablets or foul tasting liquid). We have just published a randomised controlled trial of Liraglutide, an injection therapy very successful in adults. This showed a significant and sustained improvement in glucose control, and is the first new treatment for childhood type 2 diabetes since metformin 17 years ago.

Recommendations:

1. Restore community paediatric dieticians. Since the withdrawal of this service over the last 8 years, it has become increasingly difficult to deliver consistent, regular dietetic and lifestyle advice to affected children in the community.
2. Maintain the NHS England Best Practice Tariff. This has delivered the longest sustained improvement in childhood diabetes care and outcomes in England and Wales.
3. Use targeted taxation and subsidy policies to help people make healthy food purchases.
4. Ban advertising of high sugar containing foods targeted at children.

**Keith Vaz MP** asked **Dr Barrett** if his recommendations were cost neutral. **Dr Barrett** answered that the Best Practice Tariff should be and “while Community paediatricians cost money, it is an investment that will pay for itself in the long-term.”

## Speech: Dr Billy White, University College London Hospitals

I am a consultant in adolescent medicine primarily, it just happens that I spent four years doing diabetes clinics in my training. I have done my PHD in obesity and published a review with Professor Russell Viner on ‘Type 2 diabetes in adolescents: a severe phenotype posing major clinical challenges and public health burden’.

Why is Type 2 diabetes in children so hard to manage? During puberty, insulin sensitivity decreases by approximately 30 percent, related to the increased activity of growth hormone, especially in girls. Girls are 1.3 to 1.7 times more likely than boys to develop Type 2 diabetes during adolescence.

I wouldn’t want to be a teenager now. And on top of that having Type 2 diabetes is an additional challenge. And then you go to a doctor and he gives you a hard time because you are not controlling it well. It’s hard. There is a massive stigma, school pressure, you are sleeping less, having mood disorders and being labelled a ‘bad patient’. If we don’t learn how to engage children with their diabetes, it can be hard to get them to take it seriously in later life.

The biggest issue is that your doctor will only have one medicine to treat you with. Dr Barrett is currently testing a second one. One of the things we need to do is to see how we can support research so we have more drugs on trial and getting more drugs available to treat children. This is probably extra important as our patients aren't very tolerant and need multiple drugs. Bariatric surgery is very good, but many of my patients aren't ready for it or do not want it.

We need to recruit into studies more easily, increase expertise and trial new drugs. I do worry about Brexit, apologies for mentioning it, and wonder how funding for drugs and research will work.

I am in favour of a specialist centre. Children with Type 2 will often be seen by a doctor who has less than five patients with diabetes. Specialist paediatricians need to build expertise not only with knowledge of the complications, but also with skills on how to talk with children and teenagers.

We don't just need to teach young children with obesity about healthy living, we need to teach everyone. We need it to be the normal. To know that a school meal that is unhealthy is not right. This needs to be the norm for everybody.

In conclusion, Type 2 diabetes in children is hard to help. Let's deliver evidence-based treatments. Let's trial new drugs.

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**Keith Vaz MP** asked **Dr White** about the possibility of having a GP centre as a specialist centre for diabetes. **Dr White** responded that his service is centred on primary care, and they meet once or twice a month to discuss complex patients. "I agree that primary and secondary care cannot be completely separated, everything needs to be integrated."

## Speech: Praise and Olusola Goriola, Patient voices

Good afternoon everyone - my name is Sola. This is Praise my son. We are excited to be here today as a patient voice, to share some insight into living with Type 2 Diabetes and the challenges the day to day management presents especially for a special needs child or young adult.

Praise was diagnosed with Type 2 Diabetes when he was 9 years old. Praise was significantly wetting his bed at the time. He did this for several days, this was very unusual as he would wet the bed every now and then but not every day in a row. The urine had a strange pungent smell to it. As I had a glucose monitoring meter I decided to measure his blood glucose level and the reading on the meter was alarming, it was around 17. I booked an appointment with the GP straightaway who immediately referred us to the hospital. He was on admission for about 5 days where he was treated with insulin and closely monitored.

On discharge from the hospital, we had visitations from the children's diabetic nurse who offered us valuable advice to help with managing the condition. Discussions revolved around insulin injection, diet and exercise. At the time the initial diagnosis was Type 1 diabetes as it is rare for children to be presented with Type 2 Diabetes.

We invested in a trampoline and started going for more walks, Praise lost weight drastically as a result. We also had to put a lock on the kitchen door to reduce accessibility to snacks. Praise's understanding about the condition is very limited because of the autism. He presents with significant delay in receptive and expressive language skills. So it is a challenge for us to understand how he feels. For instance he has never communicated with us whether he has a hypo or not so we often have to depend on measuring his glucose levels. I wonder if he understands the concept of hypoglycaemia. He has very poor communication skills.

In the first few months of being initially diagnosed as Type 1 diabetic, whenever I did his blood glucose tests, the measurements were always very low even though his insulin dose was very minimal. This gave me so much concern so I consulted with the hospital and was advised to reduce the dose further which we did but still the blood glucose levels were low. The nurse told me it was the "honeymoon phase" that was in place, the pancreas was still producing insulin significantly, hence the low Blood sugar level. As the level continued being low even with very low doses of insulin, I stopped giving him the insulin while still monitoring the blood sugar. The levels stabilised to normal where they should be. I then insisted on having Praise tested again to check maybe he is type 2. This I suggested as I am type 2 diabetic myself. The test was done and it came back that Praise is Type 2 diabetic. From then on the diabetes was controlled with diet and was regularly monitored with blood tests and quarterly appointments with the diabetic team. His HbA1c was always good.

Christmas time was usually the most challenging time of the year with all the food indulgence that comes with it. Over the years January blood tests results have usually been higher than normal but once we settle back into the normal diet regime everything calms down.

As Praise advanced into teenage years he had to be placed on Metformin as his glucose levels started becoming erratic. In 2017, he was placed on Novomix 30 insulin as the metformin was no longer adequate in controlling his glucose levels. Since then his HbA1c levels have remained around 6 and his GP and hospital doctor are both happy with the control.

Praise enjoys going to school and being involved in many activities that young people of his age do. His school and PAs are aware of his condition and have a care plan put in place for him. He will be going on a trip organised by his school next month to Butlins. I had to fill in all his medication forms as to how his diabetic medicines should be administered. Praise lacks the capacity to do this himself.

Sometimes it is mentally, emotionally and physically draining dealing with the management. We have had to do away with sugary foods. Praise's brothers have had to do without some snacks for the sake of their brother. It is good that they understand the consequences of unhealthy lifestyle. Unfortunately Praise doesn't understand and still manages to sneak food into his bag. As a result we monitor him closely, often checking his bag and maintaining good communication with his school about what he is or not allowed food wise. Praise still doesn't understand the complications associated with diabetes so we have to help him.

At the moment he sees the hospital doctor about twice a year and the GP about twice a year. I have to be present at all his appointments. Praise doesn't understand much of the discussions about his care so I am the one responsible for decision making. Whenever his feet are tested for nerve response my son just rests his head and smiles on, he doesn't tell the nurse where he has felt a sensation.

Praise is generally well. He uses the treadmill at home, he often goes out to walk with his dad. One of his PAs takes him out on Wednesdays to the gym and also football for young people with special needs. He was encouraged by the GP to inject himself rather than me doing it for him (Up to last month I did it for him). He has been doing this on his tummy area under close supervision. He injects himself in the morning and evening. He also uses his tablets twice a day.

It will be useful and it will make life easier if Praise had access to the Freestyle Libre system technology which would allow his sugar levels to be measured automatically without being pricked on his finger. This I think is being used on people with type 1 diabetes. I wonder if the offer can be extended to young people with special needs who have type 2 diabetes as well. It will offer less hassle when Praise is sleeping to monitor his glucose levels. This will provide his Personal Assistants and teachers the ease for monitoring whenever he shows signs of anxiety when he is out and about. It will be very useful in maintaining a good control for Praise and people with his condition. For we the carers, it would mean being able to intervene swiftly if the need arises. When going on trips like Praise will do next month, his teachers will only need to scan his skin without the need to prick for blood.

I understand that one must meet certain criteria to get it on prescription, such as testing one's blood glucose more than 8 times a day and having disabling hypos. However, I wish to request that this technology should be made available to children and people with special needs like Praise who can't so much verbalise their feelings even when they have hypos. It will go a long way in alleviating some of the stress associated with caring for them. In the long term it will save NHS money as it will lead to better control. Better control will mean improved quality of life, less visits to the hospital and will put everyone's mind at rest.

Our hope is to see Praise and other people like him thrive in good health and advance well in what they enjoy, live their lives to the fullest without the constraint of debilitating effects of diabetes.

**Keith Vaz MP** thanked Sola for talking with great passion and great feeling.

## Discussion

**Carol Metcalfe** talked about provisions in the community to identify and help children with Type 2 diabetes. She said schools are low on resources and might not be doing health checks in schools.

“There’s nothing practical for parents to do with this. The GP often doesn’t have resources either. We also struggle with engaging families with different cultural backgrounds. We need a lot of working together about this”.

**Liz McInnes MP** mentioned the recent Parliamentary debate on Public Health. “In my area, our public health has been cut greatly. We need to talk about Public Health funding. Without it, we can’t have the rest of the NHS working properly”. **Keith Vaz MP** mentioned the need to have a meeting about Health and Wellbeing Boards, as they make such a difference in the local area.

**Annina Whipp** talked about the need to look at dietary interventions that worked in the adult population and see if those can be used for children.

**James Goolnik** talked about the damage that sugar does to children’s teeth. “We talked about healthy choices and setting an example, but I don’t think we’re doing enough for children. There shouldn’t be a sugar reward for children. We need to step back from it.”

**Conrad Jarrett** mentioned the need to look at the genetic causes of diabetes. “It’s not just food, it can also be the impact of chemicals in life. We need to look at how we grow our food.”

**Bernie Stribling** said signposting is a really complex problem and talked about the need to look at structured education for children.

**Rohin Malhotra** highlighted the need for a family campaign. “We are all responsible. The word fault is misleading. A child wanting food is one thing – the parent not knowing, thinking the child needs sugar for energy, for example. It needs to be holistically about the family.”

**Buchi Reedy** talked about the need for a long-term strategy and offering remission as a first option, before surgery and drugs. “We need to offer lifestyle change as the first thing”.

**Julia Tyson** suggests that we should have calorie and carbohydrate counting in stores, restaurants and hospital menus. “Another point is incentives from the government to supermarkets and stores to give more offers to consumers on vegetables and fruits. That’s very important.”

**Dr Alok Gupta** raised the importance of screening programmes. “We don’t have screening programmes for communities like at Praise”.

**Raquel Delgado** highlighted the urgent need to target the obesogenic environment. “I think both the national and local government need to take this issue much more seriously than they are. My children’s schools are surrendered by fast food outlets. The school meals, the cake sales, etc. It’s a continuous fight against the environment, and we’re losing. We cannot put our head in the sand and hope for public health and GPs to solve this mess”.

**Martha Ford** talked about the available treatments for children with Type 2 diabetes. “I understand the worry about bariatric surgery. We would love to have research funding to do a prevention programme for children with low calories. The reason why we do bariatric surgery is because we know it works and NICE accepts it, as there is precedent for it. And it does allow you to achieve remission.”

**Margaret Khumalo** talked about working with the community, not just families. “Churches, community leaders, they dictate a lot of what can happen. We need to speak with them so they can speak with the families on the importance of medication.”

**Sola Goriola** responded to some of the comments by talking about diet guidelines to ethnic minorities. “We should also be looking more at our specific diets. They’re looking mainly at the British diet. It would be helpful for us to know recommended portion sizes for our specific meals”.

**Dr Barrett** mentioned it would be helpful if the group could advocate for research on dietary interventions on children.

**Libby Dowling** echoed comments about the need to address the obesogenic environment. “If you have a condition that is aggressive, causes complications, causes you to die earlier, and can be prevented, why are we not doing more about it? Because people think *its just diabetes*”. **Keith Vaz MP** agreed with **Libby**’s comment. “We try to raise it in Parliament, but we’re never up there with cancer. You know the tsunami is coming, but we’re not doing enough about it.”

**Dr White** highlighted how the government has been really effective about banning cigarettes. “Why can’t we do enough to ban unhealthy food?”