CHILDREN WITH TYPE 2 DIABETES

26th July 2019

APPG FOR DIABETES

About the All Party Parliamentary Group for Diabetes

The All-Party Parliamentary Group for Diabetes (APPG Diabetes) is a nonpartisan cross-party interest group of UK parliamentarians who have a shared interest in raising the profile of diabetes, its prevention and improving the quality of treatment and care of people living with diabetes.

This is not an official publication of the House of Commons or House of Lords. It has not been approved by either the House or its committees. All-Party Parliamentary Groups are informal groups of Members of both Houses with a common interest in particular issues.

Officers of the All-Party Parliamentary Group for Diabetes

- Chair: Keith Vaz MP, *Leicester East*
- Vice-Chair: Jim Shannon MP, *Strangford*
- Vice Chair: John Howell MP, *Henley*
- Co-Secretary: Liz McInnes MP, *Heywood and Middleton*
- Co-Secretary: John McNally MP, *Falkirk*
- Treasurer: Baroness Ludford

Special Advisors and Ambassadors

Anna Taylor, Executive Director, the Food Foundation
Dr Gerry Rayman, Consultant, Ipswich Hospital
Jimmy Desai, Pharmacist
Luvjit Kandula, Chief Officer, Leicestershire and Rutland Local Pharmaceutical Committee
Professor Heather Daly, Nurse Consultant in Diabetes Research
Dr David Unwin, General Practitioner, Southport
Vera Labelle, Practice Nurse
Ben Moody, Head of Programme, Health and Social Care, Tech UK
Professor Nadey Hakim, Cardiologist, Imperial College London
Councillor Emma Clayton, Founder, UK Diabetes Network
Duane Mellor, Senior Lecturer in Human Nutrition, Coventry University
Paul McArdle, Lead Clinical Dietitian & Deputy Head of Nutrition, Birmingham

Contact details

Email: diabetes-appg@outlook.com
Website: www.diabetes-appg.co.uk
Twitter: @APPG_Diabetes

Key diabetes facts

- In the UK an estimated 4.6 million people across the UK are living with diabetes. An additional 1.1 million people are expected to have diabetes but undiagnosed, this is primarily Type-2 diabetes.
- Since 1996 the number of people diagnosed with diabetes has doubled, from 1.4 million to 3.8 million.
- Of those 4.5 million in the UK diagnosed with Diabetes it is expected that 10% have Type-1 diabetes and 90% have Type-2.
- When looking at genetic predisposition more than 85 per cent of Type 1 diabetes occurs in those with no previous first degree family history, the risk among first degree relatives is about 15 times higher than in the general population.
- The risk of a child developing diabetes if their mother has it is about 2–4 per cent higher than the average, if the father has it is 6–9 per cent higher and if both parents have the condition is up to 30 per cent higher than average.
- Type-2 diabetes can also be affected by genetics have a genetic pre-disposition. Those with diabetes in the family are 2-6 times more likely to develop the condition than those without history in the family.
- Diabetes is a condition which is expected to affect 1 in 10 people globally by 2040, equalling 642 million. This will put diabetes on a par with the number of people being diagnosed with cancer by 2040. There is expected to be 1 in 2 adults across the world undiagnosed with Type-2 Diabetes. The International Diabetes Federation (IDF) has estimated that in 2015 seven countries have more than 10 million people with diabetes; China, India, USA, Russia, Indonesia, Mexico and Brazil.

Reports published by the APPG for Diabetes

- Research into Type 1 Diabetes (2019)
- Prioritisation of diabetes for government and the NHS (2019)
- International Diabetes Summit (2019)
- Assessing the Diabetes Transformation Fund (2018)
- Flash Glucose Monitoring: what's next in Diabetes Technology (2018)
- Diabetes and Mental Health (2018)
- Reversing Type 2 Diabetes (2018)
- Diabetes and Podiatry (2018)
- Emotional and Psychological Support for people with Diabetes (2018)
- Next Steps for Childhood Obesity Plan (2018)
- The Future of Inpatient Diabetes Care (2017)
- Safety and Inclusion of Children with Medical Conditions at School (2017)
- Industry Action on Obesity and Type 2 Diabetes (2017)
- Levelling up: Tackling Variation in Diabetes Care (2016)
- Taking Control: Supporting People to Self-Manage their Diabetes (2015)

Children with Type 2 Diabetes

A session of the All-Party Parliamentary Group for Diabetes took place on the 16th May 2019 on Children with Type 2 Diabetes to discuss challenges around diagnosis, management, monitoring of Type 2 diabetes in children & young adults and the role of Government in tackling childhood obesity and preventing Type 2 diabetes.

Key witnesses;

- **Professor Timothy Barrett,** *Professor of Paediatrics, University of Birmingham*
- **Libby Dowling,** *Senior Clinical Advisor, Diabetes UK*
- **Dr Billy White,** *Paediatrician and Consultant, University College London Hospitals*
- **Praise and Olusola Goriola,** *Patient Voices*

Professor Timothy Barrett, Professor of Paediatrics, University of Birmingham and Honorary Consultant Birmingham Women's and Children's Hospital NHS Trust

> ***"Most children that I see with obesity, don't want to be fat, have low self-esteem and high rates of stress and depression." – Professor Timothy Barrett***

Professor Timothy Barrett runs a fortnightly clinic where he focuses on children and young people with type 2 diabetes. His 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?

National Paediatric Diabetes Audit states there are about 30,000 children and young people with type 1 diabetes in England and Wales, but less than 1,000 with type 2 diabetes, so type 2 diabetes is seen in less than 3% of all childhood diabetes. Despite this small overall proportion, 2 surveys of the British Paediatric Surveillance Unit show that the number of new presentations 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?

Professor Barrett and his colleagues described the first children diagnosed with type 2 diabetes, at City Hospital, Birmingham, in 2000. He then went on to do a national case finding survey of 200 affected children in 2012. His findings showed that less than half affected children are white, as it disproportionately affects children from ethnic minority backgrounds, particularly South Asian, Middle East and black children. It also 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 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?

There are many families that 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, where this is 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, a fifth have protein in their urine, and at least 1 in 10 have fatty liver disease. The natural history of the disease is that it gets worse over time. 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 showing 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 like moderately fast walking, housework, dancing, exercise bike, etc. 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. A recently published randomised controlled trial of Liraglutide, an injection therapy very successful in adults 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.

Can’t we put everyone on low calorie diets?

- Many studies have shown it is very hard to achieve weight loss in children and young people who are growing and naturally gaining weight at this age.
- Compliance- high drop-out rates in adult study, would be even higher in this group who struggle to comply due to other life pressures.
- The low calorie part of the study was for a limited period; the true benefit was in breaking the cycle of unhealthy food habits, and after the low calorie period, introducing healthy eating behaviour.

What about low carb diets?

- Low carb implies high fat and rise in cholesterol, feel more full and lose weight but lifetime health risks of a high fat diet are unknown; and is very expensive for families from the poorest sections of communities to do.

What about bariatric surgery?

- Modern techniques such as sleeve gastrectomy is probably better and less invasive than old Roux-en-Y and is more effective than gastric band. But there is still a significant complication rate from surgery, and longer term complications in 23% from US TEENLABS study.

What about DAFNE? HENRY?

- Structured education that involves the whole family is most likely to work, if you can persuade them all to engage.
- Best to have bespoke education programmes. Their team conducts a 30 hours face to face from diagnosis, with mixture of dieticians, nurse, doctor, quiz's, practical sessions, and adolescent/youth workers.

Industry/pharmaceutical companies exploiting market

- EU legislation to incentivise companies to include children in studies through a paediatric investigation plan is generating evidence base statistics which will bring new treatments to children.

Libby Dowling, Senior Clinical Advisor, Diabetes UK

"T2 is much more aggressive in children than in adults. If we don't look after them, these children will go on to develop kidney failure, cardiovascular disease and amputations in their 30s and 40s. This will be devastating and costly." – Libby Dowling

Libby Dowling talked about the current situation where nearly 7,000 children and young people under the age of 25 have Type 2 in England and Wales as per figures released in November 2018 following reanalysing the data from both NPDA and NDA. (Note: Estimate based on reported cases of Type 2 and other types of diabetes in the National Diabetes Audit 2016-17, which captures information from 95 per cent of GP practices in England and Wales. The 715 figure from the NPDA only represents the children and young people with Type 2 diabetes receiving care from a Paediatric Diabetes Unit so is therefore an underestimate, as many children with the condition will remain in primary care).

NPDA May 2019:

- Only a quarter of children and young people (CYP) 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 CYP with Type 2 get these checks because they have higher risk of complications which appear much earlier.
- Black African and Black Caribbean children have poorer HbA1c than other ethnic groups.

- 22% of CYP 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 Cardiavascular disease (CVD)
- 34% have high blood cholesterol – risk for CVD
- 30.2% CYP with Type 2 diabetes assessed as requiring additional psychological or Child and Adolescent Mental Health Services (CAMHS) support outside of multidisciplinary team (MDT) clinics.

CYP with Type 2 are commonly

- Have Familial hypercholesterolemia (FH) of Type 2
- Are of Black African/Black Caribbean/South Asian heritage
- From more deprived backgrounds
- Overweight 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. Broadly 2 things need to happen – prevent further cases of Type 2 in CYP and look after those who already have it better.

Preventing Type 2 in CYP

Everyone wants for them and their children to be healthy, but is hard when we are being surrounded by unhealthy food options, junk food advertising and supermarket promotions and lead sedentary lives. So, we need to create a society where the healthy choice is the easier choice, and support people to make changes that could reduce 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 and on line before 9pm
- restrict supermarket price promotions for unhealthy foods
- continue to support Public Health England's sugar and calorie reduction programme
- 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 in CYP is much more aggressive 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 QOL. Also 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.

Main problems:

- We don't know how best to treat it.
- The vast majority of drugs used for Type 2 in adults aren't licensed for CYP. Some paediatricians use them off label, some don't.
- The criteria to get on a drug trail are very narrow, so many CYP don't meet them. So it's difficult to get the evidence base needed.
- 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.
- CYP 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 CYP. Consider widening acceptance criteria to allow greater participation.
- CYP 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 Type 2 diabetes should be treated in specialist paediatric diabetes centres, rather than part of a general paediatric diabetes caseload.
  (Note: Advantages of this include a concentration of patients allowing expertise to develop, relevant, 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. Also specialist centres won't know about local services/support for weight loss/keeping active)
- 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 CYP and get directly from them what they want and ned to manage their Type 2.

Dr Billy White, Paediatrician and Consultant, University College London Hospitals

---

"We don't just need to teach young children with obesity about healthy living, we need to teach everyone."– Dr Billy White

---

Dr White is a consultant in adolescent medicine, spending four years doing diabetes clinics during his training. He has obtained a 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.

We can agree that being teenager today can be hard and on top of that having Type 2 diabetes is an additional challenge. 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. And with Brexit fast approaching, we must wonder how funding for drugs and research will work.

We also need to focus on specialist centres. 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.

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

Praise and Olusola Goriola, Patient voices

> ***"Sometimes it is mentally, emotionally and physically draining dealing with the management." – Olusola Goriala***

Sola and her son Praise provide 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. Once the family discovered their son had diabetes, they had visitations from the children's diabetic nurse who offered valuable advice to help with managing the condition - insulin injection, diet and exercise. The initial diagnosis was Type 1 and not Type 2, as it is quite rare at his age to be Type 2.

They invested in a trampoline and went for walks, resulting in a drastic loss of weight. The family also decided to put a lock on the kitchen door to reduce accessibility to snacks. The whole of the family has had do away with sugary foods. It is important as a family that they support and understand the consequences of unhealthy lifestyle. However Christmas time is usually the most challenging time of the year with all the food indulgence that comes with it.

For Praise, the understanding of his condition is very limited because of the autism. At times he can have very poor communication skills. When the family found out he was a Type 2 diabetic, they controlled the diabetes with diet and was regularly monitored with blood tests and quarterly appointments with the diabetic team.

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. 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.

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. At the moment it is being used on people with type 1 diabetes. It is important for cases like this that the offer be extended to young people with special needs who have type 2 diabetes. It will offer less hassle when Praise is sleeping to monitor his glucose levels. This will also provide his Personal Assistants and teachers the ease for monitoring him.

The family wishes 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.

The ultimate goal 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.

Audience discussions:

The Chair asked ***Professor Barrett*** if his recommendations were cost neutral. ***Professor 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."

The Chair 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."

The Chair asked ***Libby Dowling*** 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."

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”. ***The Chair*** 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 Reddy 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 such as Praise’s”.

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”.

Professor 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 it’s just diabetes”. ***The Chair*** 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?”

Recommendations:

- 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.
- Maintain the NHS England Best Practice Tariff. This has delivered the longest sustained improvement in childhood diabetes care and outcomes in England and Wales.
- Request the National Institute for Health Research, Health Technology Assessment programme, a commissioned call for research into nutritional interventions in childhood type 2 diabetes. This would support a proposal to investigate the effects of a low-calorie diet, or possibly a low carbohydrate diet.
- Create a society where the healthy choice is the easy choice by the Government acting on the measures in the Childhood Obesity Plan.
- Prioritise research in to the safety, effectiveness and acceptability of medications to treat Type 2 diabetes in children and young people.
- Ensure children and young people with Type 2 diabetes have access to expert clinicians who are trained to manage and research the condition and the challenges it presents.
- Young people with type 2 diabetes who may also have other complex needs should have access to technology which would allow their sugar levels to be measured automatically without finger pricking. This is already being used on people with type 1 diabetes. It will be very useful in maintaining a good control for their diabetic condition and provide a non-invasive way to monitor them when they are asleep.
- Dieticians work more with the community based on their ethnicity to discuss their types of food, calorie content, method of preparation and portion control to educate people and make them more aware of the benefits of making healthy diet choices.