

61. Dr Peter Swift

(1) Tell me about your background.

I was born during the Second World War, when my father was serving with the British Army. And I was born in Shrewsbury, in a county called Shropshire, where my mother was living at the time. But my father was a teacher, and he came to Leicester to work and to live, with the family, and so I lived in Leicester from 1946 through to 1962, when I left Leicester to go to university. Both my parents were teachers. My father actually taught at the secondary school - the grammar school - that I attended; he was actually the Assistant Headmaster there. Very sensible man, who decided never to teach his children, but he obviously influenced my life a great deal. In particular, I think he influenced me towards going into medicine, because I think he always actually felt that he wished he had been a doctor. And so then, after leaving grammar school, I went to Cambridge University, to Downing College, which has a very strong tradition of medicine. And actually, I was taught by a very famous - he was a lecturer at Downing, called Nick Hales - who became very famous in the diabetes research field. And, after three years in Cambridge, I then moved to Guy's Hospital to complete my clinical training. And I suppose it was there that I first, as a medical student, came across people with diabetes.

(2) What year did you first encounter diabetes?

Well, I qualified as a doctor in 1968, and so I suppose, as a medical student, I came across a number of adults with diabetes in '66, '67. And I do remember them as being often both young and old people, who had rather crippling complications, vascular complications, like bad blood vessels in their legs, and retinopathy. And indeed, quite a number, I think, with renal failure. And this was a pretty shocking introduction to diabetes, to a medical student. And, of course, it linked up with a great deal of teaching in pathology that I had received at Cambridge. I did... actually I did a BSc in pathology, and we learnt a great deal about diabetic complications. And so, they were the first experiences of seeing adult people with diabetes. I'm not sure that I can ever remember seeing a child with diabetes, at Guy's Hospital, in my studentship; in fact, I'm pretty sure I didn't.

Were the adults people who'd had it from childhood, or a mixture of the two?

That I can't remember, but I suspected... Well, I think the implication was that diabetes came on in adulthood, and, fairly quickly, it led to these disastrous, distressing complications. And I think the implication was, also, that people with diabetes didn't look after it, and therefore they got complications. And that was always, I think, a background which was a very negative, sort of, aspect to the disease and disorder. And I guess, in many ways, in those days, this is one reason why many doctors did not want to go into the specialty of diabetes: diabetology.

(3) So, why did you specialise in diabetes?

Well, this is a both slightly amusing and interesting story, I think, that when I qualified, I wasn't quite sure what specialty I wanted to go into. It was either general practice, to be honest, or paediatrics. But I was advised to take the adult MRCP postgraduate examination. And as part of that training, I came back to Guy's - having moved away for a little while - came back to Guy's, to work as, what was called, a Senior House Officer. And this was fairly soon after qualifying. And I remember being put in an outpatient clinic, which was actually run by some very famous adult diabetologists. I'm not sure that I should mention names, but there was Christopher Hardwick, who was very well known in diabetes circles in Guy's, and indeed Harry Keen, who was then, and was to become, one of the most respected and famous diabetologists in the whole world. Now, this clinic was run in a very old-fashioned, dilapidated building, which was very unpleasant to work in. And the clinic itself, seemed to me, to be not very well organised. Here was I, as a very immature, inexperienced house officer, seeing patients who were coming in from all over London, once or twice a year, and I didn't know anything about the condition. I just thought that these people, these poor people, were getting a very bad service from Guy's Hospital. And it really almost put me off diabetes for the rest of my life. But things changed quite dramatically, that when I was a senior registrar in paediatrics, some ten years later or more, a new consultant came to Bristol Children's Hospital, and he was a specialist in diabetes and endocrinology - paediatric endocrinology. And he said to me, soon after arriving, "I'm not quite so interested in the diabetes as I am in endocrinology. I think you, as senior registrar, should set up the first diabetes - specialist diabetes - clinic for children in Bristol", which I did. And, after a few weeks, I began to feel that this was a specialty that was absolutely fascinating, in every respect. And I went to the consultant, and

- (4) said, "well, what about this diabetes? I think it's very, very interesting, and extremely difficult for the children and parents". And he said "well, why do you say that?" And I said "well, because diabetes is very difficult to control, and it has so many influences, particularly the influence of the family, of the psychological aspects, the emotional aspects, and the social influences on diabetes". And he said "oh, no, no, no. Really, once you get the insulin dose right, everything else will fall into place". And I hesitated, and I said "I'm sure that's not true". He said... I said "you know, some of these parents are struggling hard with insulin injections and doses, but still the diabetes doesn't seem to be particularly well controlled". Of course, in those days, it was difficult to assess control, because we were basing this on urine testing. There were no blood tests in those days; this is 1976, '77. And so he said "no, it's very important to get on with getting the dose of insulin correct". Anyway, a few years later, after the establishment of this clinic, this same consultant was actually publishing papers on the psychosocial aspects of diabetes - very well, I might add, as well - because he became a very well-known paediatric endocrinologist and diabetologist, over the succeeding years. And so, my whole life was changed as a consultant, or as a paediatrician, by being introduced to the

possibility of looking after - helping - parents and children with diabetes. And then, soon after that, I moved on to my final placement in senior registrar paediatrics, in Exeter in Devon. And there tried very hard to set up another paediatric diabetes clinic, but the consultants really were very reluctant and resistant to that, in that they liked to look after one or two or ten children with diabetes on their own, without a specialist clinic being available. It did actually get off the ground, just in the last few months before I left Exeter. But, while I was in Exeter, I met another senior registrar, in adult medicine, called Charles Fox, who again has become a very, very prominent member of the diabetes community. He works in Northampton, not far from here. And he and I set up the first parents' support group for the British Diabetic Association, in Exeter. And I remember - and I still have pictures - of Charles and myself talking to parents in that group. And this was a very pleasant, and really important aspect, I think, of one's early career in paediatric diabetes.

- (5) Before we move on to talk about those parents' groups, I'd like to back-track to what you described as those dreadful clinics at Guy's. Can you describe them?

Well, as I said previously, the outpatient clinic was held in a very antiquated part of Guy's. I guess the buildings would have been Victorian, and they were scruffy, they were small, they were crowded. There seemed to be a lack of organisation. In those days, of course, very often, a whole host of people would be given appointment times at exactly the same time. You know, come to the clinic at four p.m., and then there'd be a list of eighty patients all waiting there until they were seen. And then, of course, after an hour or two's wait, they would see me - a junior house officer, knowing very little about diabetes. I do... I remember, after one or two of these clinics, going in to talk to people like Dr Christopher Hardwick and Harry Keen, and John Jarrett - all famous diabetologists; not so famous in those days, but have been - and just feeling that we were all, I suppose, trying to grapple with an extraordinarily difficult, lifelong disease, and not doing it very successfully, and not having the mechanisms to help patients to really get a grip on their diabetes.

In those clinics in the late 1960s, early 1970s, would there have been any ancillary services? Would the patients have seen a dietitian, podiatrist, and so on?

I think that the ancillary services, then, were either completely absent, or very, very minimalist. I suppose, you know, the only people who made contact with the patients, there in the clinic, were perhaps a nurse, who might have taken the blood pressure, or urine sample, of course. That was, you know, the most... one of the most important things for the patients: "bring in a urine sample and we'll test it for sugar and protein". Yes, I'm not sure that they even took blood pressures, because I remember having to do that myself, and thinking "you know, well, they're getting their blood pressure checked once a year, by me. That's pretty inadequate and rather a hopeless task". But yes, the urine testing was then, of course,

- (6) one of the few things that could detect, for instance, proteinuria - but that would be gross proteinuria - to see that... whether the renal function was... And, I suppose, we all did an annual - or every two or three years - did a blood test to measure serum creatinine, or something like that. But it was very, very minimalistic care, without a great deal of real help to the patients. And then, I suppose, my next real time I did come into contact with children with diabetes was when I was a registrar in Sheffield Children's Hospital, working, again, for one or two famous paediatric professors: Professor Ronald Illingworth, who did not have an interest in diabetes, but was an extremely influential developmental paediatrician. And then the person who did run a diabetic clinic was Frank Harris, who later became Professor of Paediatrics in Liverpool University. Now, I know that Frank Harris did run a children's diabetic clinic in Sheffield - probably one of the first, I'd guess. This would be 1972. But I don't think I ever visited that clinic. But I do remember one or two children being admitted, on a regular basis, to our paediatric wards, where we were supposed to try and look after them. And there were one or two, in particular, who seemed to come back and forth almost every week, because their diabetes was out of control. And again, harking back to what I said earlier, there was always this in-built criticism, perhaps, that these children, these parents, were inept, and weren't able to cope with their diabetes, and therefore, you know, they were admitted to hospital. A very negative aspect of doctors' and nurses' attitudes towards diabetes, which, I have to say, still exists, in many parts of medicine. But those of us, I think, who look after children and young people with diabetes, realise that there are so many reasons why diabetes does get out of control, particularly because it is so difficult to manage in a strict and really satisfactory manner.
- (7) Right, so from Sheffield, you went to Bristol, and then, as you've said, to Exeter. Tell me more about your time at Exeter, 1977 to '78.

Yes, in 1978, I think those of us who were interested in diabetes read two important papers. Number one was this description of the glycosylated haemoglobin: HbA1c; HbA1, as it was, initially. And how exciting it seemed that we would have this gold standard measurement to have at our fingertips, to help to show patients how their diabetes was being controlled, from a glycaemic point of view. And so I tried, with Charles Fox, to set up an HbA1 assay in Exeter. And, I have to say, it was a complete failure, because I was working so very hard on general paediatrics and new-born babies, and so on, I just didn't have the time to devote to trying to set up this assay, despite having some help from the chemical pathology laboratories. And the other very, very important paper that was published, I think just before I left Exeter - and we had a journal club, and I remember presenting this to the journal club - was the world-changing papers on blood glucose monitoring, from Robert Tattersall in Nottingham, and Peter Sonksen at the St Thomas' Hospital in London. And I remember presenting this paper to a paediatric journal club, and actually saying, "well, I think blood tests are going to be very difficult for children to do". And I repeated that, some... a

couple of years later, when we had a very big meeting in Nottingham, actually, about blood glucose monitoring. And, of course, my views have changed over that, but in those days, I really did think that children would find finger-pricking extremely troublesome and difficult. I think they now do it better than many adults, but that's history. And going back to Exeter, then: I also had to do general paediatric clinics down in Torbay, in Torquay - a small district general hospital. And one of the things that struck me there, about diabetes - and, if you remember, I'm already very interested in diabetes, at this stage - is that the children and parents brought

- (8) in some very nice urine testing books, that they'd coloured in with their crayons of different colours. I have to say, most of them were orange, because the urine testing of sugar was, if there was lots of sugar in it, it went an orange colour, and they filled in their books with lots of orange. And I thought at the time, "this is a pretty inadequate way of looking after their diabetes". But they were trying, and they were doing what was then available; a very poor way of looking after their diabetes, as we've learnt since. Although, having said that, if one became rather more strict about this, and said that perhaps if one could obtain 50 or 75% of blue urines, ie no sugar, then almost certainly the diabetic control - the metabolic control - was fairly satisfactory. Especially if, of course, overnight, when one woke up the next morning, the urine test was blue, and therefore no sugar was being passed throughout the night, which was pretty good control, especially for children. And so, that was Torbay; that was Exeter. And then, I obtained my first consultant job in Leicester. . .

I'll just interrupt you, because I'd like you to tell me about those parents' groups in Exeter.

Oh yes. Now, Charles Fox and I set up this first parents' group. And so we organised just one or two meetings of parents to talk about diabetes. And I remember there were one or two sets of parents who were very, very enthusiastic about the possibility of their children meeting other children with diabetes, getting together at these meetings, learning more about diabetes. But I think they were early days, and Charles and I then left Exeter to go our different ways.

- (9) Right, then talk about your move to Leicester.

Yes, well, I was appointed as a consultant in Leicester. And I had come up to visit the Leicester consultants some months before, and realised that - and I hadn't known this before, actually - that there was a very strong history in Leicester in caring for people with diabetes. When I came to Leicester, before the interview, I met Dr John Hearnshaw, who had been appointed as an adult physician in diabetes in 1967. And he was obviously extremely influential in the care of both children and adults with diabetes. Now, this was a little unusual, because paediatricians had, in the past few years, taken over the care of children with diabetes. John was actually extremely critical of paediatricians looking after children with diabetes, because he felt - quite rightly - that they didn't see

diabetes as a very serious disease, and didn't look after children with diabetes particularly well. So, John - like his predecessor, who we will come to later, Dr Joan Walker (see Extras) - began to see children, right from day one, in Leicester. And so, I heard... I met John, and he, I think, welcomed a paediatrician to come and help with the children's services, although I was never quite convinced of that! And he also talked to me about Joan Walker. Now, before I left Exeter to come to Leicester, I met Joan Walker in her home. She was then retired for many years, of course, in Lyme Regis. And my wife and I, and our three children, went down and had a lovely afternoon with Joan. She was absolutely delighted to realise that a paediatrician would be going to Leicester to help with the diabetes service. She felt that it was a culmination of many of the things that she had begun, and it certainly made me even more enthusiastic in trying to set up a good children's service, or build on the children's service in Leicester.

Can you tell me

- (10) more about what you learnt of Joan Walker's work, before you were in Leicester?

Joan, I think, was a remarkable woman. And I learnt, fairly rapidly, that she had been given an appointment during the Second World War as a physician, looking after people with diabetes. Partly, because nobody else wanted to do it, partly because, of course, many of the men - male - physicians had gone off to war, leaving this lady doctor - without MRCP - holding the fort, as it were. And she was given the poisoned chalice of looking after people with diabetes. But, of course, she took this up with enormous enthusiasm, courage, intelligence. She set up, very early on, epidemiological studies of diabetes in Leicestershire. Other people may have remarked that she set up, I think, one of the very first epidemiological studies, in a village called Ibstock in Leicestershire, that actually was connected with Harry Keen, as well. He came up from London, I think, to help with that study. And Joan was remarkable, in that she realised that in order to cope with diabetes, you needed help from a wider team - the doctor himself or herself couldn't do it. And so she appointed the very first community health visitors, who would specialise in diabetes. I think the first was appointed in 1953 (53. Joan Wilson); maybe a year or two before that. I've always said that these were the first in the world, but that is not true. The first diabetic specialist community nurses were, I think, introduced by Joslin, in the USA, in the 1930s. But these in Leicester were certainly the first in the UK. And there are, of course, pictures in Joan Walker's book - a Chronicle of the Diabetic Service - of these early diabetic health visitors, community health visitors, who were appointed as specialist nurses for the diabetic community. Now, in relation to children, Joan did not have any hospital beds to her name. She wasn't accorded that privilege, because a) she was only a woman, and b) this was the diabetes service - not very well supported, and c) she hadn't got MRCP, and so really wasn't, strictly speaking, a consultant specialist. So, Joan realised that she had to treat diabetes out of hospital. And this applied, also, to the children. And so, whenever children were diagnosed with diabetes, with a positive urine test,

and thirst and polyuria, and losing a bit of weight, she treated them out of hospital with the help of her specialist nurses. And I think this was - certainly in the UK - the first time that anybody had had the courage to treat diabetes in children out of hospital. And so, this was the service that Joan set up. It became very famous, really, but not followed by many paediatricians around the country, or other adult physicians looking after children with diabetes. But then, when she retired in 1967, John Hearnshaw took over this mantle with tremendous enthusiasm, and started visiting children at home on the very first day of diagnosis. He spent many, many hours going into children's homes, often late in the evening, introducing them to insulin - confirming the diagnosis, of course, and later, not only with urine testing, but blood testing - introducing them to the insulin injections, and getting them started in a very good way in their own homes. And that is the background into which I was introduced in 1979.

(11) What happened after you arrived in Leicester in 1979?

When I came as a consultant to Leicester, I was appointed, to the first position, as a consultant with a special interest in children's diabetes. I realised that John Hearnshaw was, as I have said, looking after many of the children - probably two-thirds of the children - with diabetes from the day of diagnosis. And I realised that I ought to join up with him, rather than compete in any way. And so, I realised that I should join with him, and we set up, together... or he was already doing a children's clinic - every month, I think it was - on a Saturday morning. And so, I started going to this clinic, and sitting beside him, once or twice, to see how he organised children's diabetes. And then, obviously, as time went on, we had our separate lists, and... but did the clinic together - until he retired - on a Saturday morning. And also, I went out on a newly-diagnosed children's home visit - a domiciliary visit - to see how he organised that. And subsequently, I did many domiciliary visits myself, at the point of diagnosis. Now, also, I did feel that I wanted to set up my own children's diabetic clinic, which I did. And I don't think John really appreciated that, and didn't really want me to set up some competition. But it was quite clear that at least a third of children had to be admitted to hospital at diagnosis, because they were ill, and dehydrated. And so, those children I tended to see in my clinic; some on the Saturday morning. And at this time, in 1979, Leicester already had an assay for HbA1, which was up and running, and very useful indeed. This was the first time I'd been able to use HbA1 as a standard of care and assessment of diabetic control. Moreover, we were just, then, beginning to introduce blood glucose monitoring in the children, with some very old-fashioned - now, very old-fashioned - blood glucose monitoring machines. I think the first one was using Dextrostix, and the Dextrometer, or something, it was called. In my first year in Leicester, John had said to me, it would be very useful for me to go on a diabetic children's holiday, with the British Diabetic Association. John had been on many of these holidays himself. And I remember being called up - about June 1979 - by the British Diabetic Association, saying could I go to Denmark with eighteen adolescent diabetics.

- (12) And I said yes, I would go in - I think it was July or August - for two weeks. And we all met up in London - children from all over the country, all in the adolescent age group. And I remember my first experience was travelling by bus, overnight, from the Dutch coast, across Germany, into Denmark. And at about three a.m., the seat in front of me started shaking and rocking. And I realised, fairly quickly, that the boy sitting in that seat was having a major hypoglycaemic attack - the first one I'd ever come across, in practice. And so, with the help of some sugar, and also an injection of Glucagon, we got him better. And I have to say that one's first experience of going on a diabetic holiday with young people with diabetes, in that context - taking them all away to a hostel on the coastline of Denmark - was a huge educational experience, and made one realise how very, very difficult it is to look after diabetes day by day, night by night, three hundred and sixty five days a year. I remember taking with me these Dextrostix machines, and demonstrating them to the children who'd never seen them before, and trying to persuade them to do one or two blood glucose tests. And indeed, I've just remembered that, after the second trip - the next year, I went to Denmark again, with my wife and family in attendance - we did do quite a bit of blood glucose monitoring, and wrote a paper in the Postgraduate Medical Journal about blood glucose monitoring in children in adolescence with diabetes. The second trip, a year later, was almost a complete disaster, because we had one young man - highly intelligent, but unfortunately very manipulative young man - who became recurrently hypoglycaemic - severely so, both night and day. And I kept on reducing his insulin, to the extent that he was hardly taking any insulin. And I sort of realised, probably for the first time in my medical career, that this boy was probably giving himself extra insulin
- (13) to make himself hypoglycaemic, and create attention - bring attention - to himself. And I took away all his insulin from him, but, even so, he continued to go hypoglycaemic. And, of course, I thought of other diseases, like Addison's disease and Coeliac disease, but then, I think one of the other adolescents did tell me that he thought that this boy was disappearing into the toilets and injecting himself with extra insulin, despite close attention. When we arrived back in London, after that trip, I admitted the boy back into Great Ormond Street, where his consultant - a very experienced paediatrician - told me, some months later, that he was pretty sure that this boy had been manipulating his diabetes like this, because he'd done it before. But that was a very eye-opening experience, on how some young people find diabetes so very difficult, that they are forced into a situation when they manipulate their diabetes to gain attention for themselves. Now, the diabetic camps, I will talk about in a minute, but when I arrived in Leicester, there was already a parent support group. I had tried to set one up in Exeter, as mentioned previously, but Hilary Hearnshaw - who was John's wife - and John set up a parent support group in 1975. I think it was one of the first parent support groups in the UK, and, even now, there



are rather few active parent support groups of Diabetes UK. But the one that I was introduced to in 1979 was already pretty active, and met on a monthly basis to have educational talks and social activities together. And I was very impressed with this, and took over as president of this group, I think in the early eighties, when John Hearnshaw withdrew as... or retired as president. And after I had been on several British Diabetic Association national camps and holidays, I became a little critical and disillusioned. Because I thought, here we are, looking after these children on holiday for two weeks, and putting in a huge amount of effort into helping them, getting to know them, really becoming very attached to them, in many ways. And then they'd disappear to their own clinics, all over the country, and we'd never see them again. And so, I thought that it would be best to have a local camp or holiday. And so, in 1983, I went off to America for the summer holidays, with my family, and we visited four or five different American camps of different types. Some were just day camps, some were two week camps, some were six week camps, I think. And got a flavour of how they were running their camps and holidays in America. And so, I came back, in 1983, and I said to the chairman of our parent support group in Leicestershire, "what about a local camp?" They took this up with tremendous enthusiasm. And I remember visiting a few facilities, here in Leicestershire, to see where we could hold our camps, and came across the most wonderful facility, in Leicester, called Quorn Hall, which is near the town of Loughborough, that is owned by our education authority. And it is a residential house - an old Georgian house, with nice dormitories built on to the back - where I realised we were able to stay, for a few days, with our children with diabetes. And so, we set up, in 1984, this residential holiday for children with diabetes in Leicestershire.

- (14) So, the first camp was - local camp - was 1984, and so we've been doing it every year since then. It started with, I think, about thirty children attending the holiday for about three days, which quickly extended to four days. We now run it for more than fifty local children, every August, for five days. And I think, over the years, therefore, we have accommodated well over a thousand children. And our camp is unique, I think, still, in Britain, in that the majority of the organisational work is performed by parents. We have a very strong parents' group, with a wonderful team of helping parents to look after the children. And, of course, this means a huge amount of organisation, in terms of working out what activities we should have; an excellent dietitian, we've had for twenty years, assisting with the dietary and meal arrangements at Quorn Hall; and also, of course, medical and nursing staff to help from the technical point of view. And I hope that a large number of children have been supported and helped in looking after their diabetes, in the broader context, during hard physical exercise. We go walking in the county of Derbyshire, we do canoeing, ice skating, all sorts of physical activities, as well as quieter activities and quizzes and music shows, and so on, within the hall itself. Unfortunately, although we've

tried to publicise this sort of activity run by parents, nationally, I don't think it has really caught on in many other places. I know, of course, quite a number of groups around the country, where short weekend activities are organised, but nothing like five days or a week, I think, in any other UK group that I know of. The British Diabetic Association, which became Diabetes UK, of course still has its national holidays. These are fewer in number, now, than they used to be, accommodating rather fewer children, which is a shame. But, of course, they do find it difficult to recruit doctors and nurses and helpers

- (15) at their holidays. But I've always believed, myself, that these outside-the-clinic activities for parents and for children, do have a major beneficial influence on children's and parents' abilities and confidence in looking after their diabetes. And I hope that is really so, although it's difficult to prove. One of the other aspects of trying to assess the efficacy of camps is just seeing what happens to youngsters as they grow older. And in the last ten years, we've had quite a number of young people, growing up, who want to help with our holidays and camps, and they are becoming our young leaders, who are now influencing the younger children in a very positive way.

How does just five days, once a year, make a difference?

Again, that's a very difficult thing to prove, in any scientific way, but I think. . . When we first started doing the camps, we did give questionnaires to parents, both before and after camps. And some of the answers that parents gave were very interesting in showing that, even five days of a holiday, seemed to impinge its importance on the children very greatly. Even to the extent of changing dietary habits, certainly self confidence, certainly the ability to become rather more independent, and to do things which they. . . some of the parents were not allowing them to do, in terms of activities, eating, and understanding certain things about diabetes. Of course, the younger children, some of them had never given their own injections. And so, when they saw other children giving their own injections at the camp, they would do it themselves. That's a fairly simple and basic proof of some sort of progress. But, I think there's no doubt at all, in my mind, that so many of the parents wrote to us about the way that, even after five days, their children had sort of changed. They'd become more independent, more confident, and certainly gained a number of friends, that often become lifelong friends. We have experience of that. And lifelong friends, not only with the other children, but some of the other parents and helpers.

What age range do the camps cover?

Our own camps cover quite a wide age range, from seven through till, well, sixteen or seventeen. We do try to do activities for the adolescents which are different from the smaller children, of course, but they all do sit down together in the dining hall to eat together, and do a number of the activities together. With the Diabetes UK holidays, of course, they do have age specific holidays, which I

guess is more ideal. But the local holidays, because it takes up so much of our time in organisation, we can't really afford the time and energy to have different age group holidays. We'd like to, we've thought about it, but not practically been able to organise that.

(16) Can you now talk about the history of children's diabetes care, from the early 1980s?

The history of diabetes care in children, in the UK, really does not stretch back very far. When I took up my appointment in 1979, there was only one other paediatrician in England, called David Baum, who really was forging new ideas, publicising diabetes, writing papers on diabetes. That was in the very early 1980s. And he had a series of research lecturers, who was doing research with him, and some of whom have become very famous paediatrician... paediatric diabetologists, since then. But preceding David's work in England, Scotland was ahead of us, in that there were at least two, probably more, famous paediatric diabetologists: firstly Jim Farquhar in Edinburgh, and then Oman Craig in Glasgow had set up really very good children's clinics. Jim was very involved in setting up, what was called, the Firlush young people's experiment, which is a summer camp for adolescents, a bit later. But he was publishing papers in the seventies, probably the sixties, on paediatric diabetes. Oman Craig in Glasgow, in contrast, did not publish a great deal of work, but was running a very excellent, very sensitive to parents, type of clinic for many years, and wrote this all up in a marvellous book called *Childhood Diabetes* in the early 1980s. And certainly on meeting Jim Farquhar, on several occasions, one was very impressed indeed at the huge commitment he had made towards childhood diabetes, in the late sixties and early seventies. So, David Baum was really, I suppose, shall we say, my guru for childhood diabetes, in the late seventies and early eighties. And he and I discussed trying to assess the services for children with diabetes. He did try a small questionnaire survey, I think it was in 1984, but the response rate was not very great. So, in 1988, following a great deal of discussion and planning, we did do our first survey of paediatric services in the UK, and distributed quite extensive questionnaires through the British Paediatric Association and the BDA, and got a huge response rate. It was, I think, it was 93% of paediatricians responded to this. And so we did get an idea of how many clinics there were, what sort of services were being provided, and a description of the type of standards that were being looked at in paediatric diabetes. And, I have to say, that the standards were not terribly high. And we published this paper, and subsequently other papers, showing how the services within paediatric diabetes were changing over subsequent decades.

(17) In what ways were the services not very good?

Firstly, we found that the number of specialist children's diabetic clinics was relatively small. I can't remember the exact figures now, but I think at least 40% of the clinics, which were where children were being seen, were general paediatric clinics. That means that the children with diabetes were being seen in clinics, alongside children with asthma or epilepsy or cerebral palsy, or whatever. They

weren't in specialist clinics. And also, rather few of them were using HbA1c as the gold standard of care. Rather few of them had specialist nurses and dietitians, and hardly any had any psychological and psychiatric help in clinics. Unfortunately that still remains. But when we reported all this, we gave some emphasis to the need for trying to set up specialist children's diabetic clinics, looked after by consultants who had a special interest in diabetes. It seemed very unfair and unrealistic to expect general paediatricians, who were looking after other interests, to give any special time or expertise towards diabetes, if they were in general paediatric clinics, and so this was the push. And I have to say, in our last survey, in 2004, I think the situation has changed dramatically, in that something like 96% of children with diabetes are now seen in specialist clinics, long before time. And although there have been major improvements, also, in the number of clinics who have specialist nurses, the number of nurses is still not adequate. Some clinics do not have specialist paediatric dietitians, and very few have specific help from mental health workers. And these are still considerable deficiencies, which we have reported, just recently, in the medical press.

(18) What kind of mental health support do children with diabetes need?

I think I became aware that, as I said earlier, that diabetes in children, and in adults, imposes enormous psychological demands on people. I became aware of this, you know, right at the beginning of setting up the children's clinic in Bristol. And I think it has been shown, now, in good scientific studies, that the type of insulin you take, the insulin regime you're on, has very little effect, overall, on diabetic control. Much more important is the way that you use different insulins. And therefore, the way in which you manage the diabetes - you manipulate the insulin, you change the insulin, you adjust the insulin and food - depends on your confidence, on your emotional stability, on family help, on issues which are to do with the psychological background of a child or young person. Now, therefore - because, I have to say, that increasingly, in our society, there had probably been rather less support for many children at home, with broken families, and difficulties within families, difficulties in education - that more and more, one has realised that many children, many parents, need a great deal of emotional support and counselling in helping them to get through what is this very, very difficult disorder of... disease of diabetes, and to cope with it and manage it well. So, ideally, I think within any specialist clinic, we ought to have the help and support of a psychologist or a child psychiatrist or a good counsellor, to deal with these issues. But unfortunately, here in Leicester, for instance, I've struggled really hard to try and get specialist help like this, and failed miserably, because, either they just don't exist, such specialist people, or there is no money to appoint them. And unfortunately, this has applied throughout the whole of the UK. I think the latest figures were that only about 22% of clinics have specialist help from mental health professionals. This is very different from on the continent, where in countries such as Holland and Denmark and Sweden, they have much heavier help, much more positive help, from mental health professionals, to help in their specialist clinics, such as diabetic clinics.

And this is one of the major disappointments, I think. So, if we were unable to have help from specialists in the mental health services, what did we do? Well, I guess a great deal of our clinic time was taken up - not only with the nurses and of an excellent dietitian, who had a psychology degree, and myself - struggling, really, to help parents come to terms, in psychological emotional terms, with the difficulties of managing diabetes. But this, in many ways, is inadequate. What is really needed are specialist mental health workers, like psychologists, who can teach us, as medical specialists, nursing specialists, the best ways of coping with psychological problems in the parents and children that we're dealing with.

(19) Can you give some examples?

Well, I think it's true to say that, when one really takes an interest in children, parents and diabetes, you often realise, from day one, that certain families are going to find it extremely difficult to cope with diabetes, on top of other problems. Now, at that point, it would be very useful to have real expertise in psychological management and counselling, for such parents and such children. Then there's the other issue, of course, that diabetes has such a huge impact on both young people and parents, that, of course, a significant number of parents, particularly the mothers, go into a phase of depression; sometimes severe, sometimes mild. And again, at that time, it would be very helpful to have expertise in intervening in those difficulties, and recognising these psychological problems more readily and more accurately. And then thirdly, the other aspect is, of course, in adolescence, when all children have difficulties, in this adolescent period of growing up, changing, becoming more independent. When diabetes is imposed upon that, the difficulties often become very much more problematic. And there again, the expertise of psychological counselling, support and help would - and is - very beneficial. There are many studies, now, that are published, in terms of interventions in adolescence, and with parents, that may help to alleviate some of these huge difficulties of looking after diabetes in young people. And unfortunately, we, in the UK, have not - until very recently - have not had the finances, the resources, to set up these very good interventions to help in the psychosocial contexts.

(20) What have been the major changes over the last thirty years?

I think, overall, the major change that I've seen - particularly in the last fifteen years - has been the change of priority of diabetes in the minds of many people in medicine. This is, of course, a very fortunate thing, in that, as I was saying earlier, I think certainly prior to the 1980s, diabetes was seen almost like the Cinderella of services. People didn't want to become specialists in diabetes - certainly not in paediatrics - and diabetes was almost always relegated to the bottom of the pile of medical specialties. I do see, both in adult diabetes and certainly in paediatrics, that diabetes has become a very much more, almost glamorous specialty to be in, because... and I suppose that's because we now have better means of trying to control it. We have better means of establishing standards, such as looking at glycaemic control, with HbA1c. We have a good number of medications - in adult diabetes, particularly - to control blood pressure

and look at renal function, and so on. And, of course, all these have become more important, on the back of landmark studies, such as the DCCT and UKPDS, which have proved, beyond any shadow of doubt, that glucose control is of paramount importance. But then, of course, it has been recognised, over the last twenty or thirty years, how important the lifestyle changes are in diabetes, and trying, as I was saying earlier, to help and support patients, a) to understand the condition, and b) to support them psychologically and socially, in looking after what is the most demanding disease imaginable. Both in Type 1 and in Type 2 diabetes, huge lifestyle changes are necessary in order to maintain really good control over the years. Now, in children,

- (21) of course, nearly all the diabetes is Type 1. But another of the major changes that has occurred, and is occurring at a rapid rate, is the introduction and the emergence of Type 2 diabetes. In this country, it's not very big at the moment, but certainly in America, very large numbers of young people are developing Type 2 diabetes, with complications, because of the global epidemic of obesity. Of course, superimposed upon all this, in the changes over the last thirty years, is that Type 1 diabetes has increased very, very considerably in incidence, in this country and elsewhere. Our incidence, now, of over twenty per hundred thousand children, is in the middle to upper range world-wide. Still the incidence in the Far East is very low, but in some Scandinavian countries - such as Sweden, and Finland, in particular - the incidence is double that in the UK. But with our large population, this means that quite a large number of children are developing diabetes, and at a younger age, and this has imposed considerable stresses and strains on our services. And one of the ways it influenced me, of course, is that I used to try and do domiciliary visits on all the chil... as many children as possible, when they first got diabetes, and this became increasingly difficult, especially as one also increased in age. Going out late in the evening on a regular basis, to see children at home, was often - and that was out of hours, of course - was often quite difficult. Again, the other influence, which I may have mentioned before, of the increasing importance and recognition and understanding of diabetes have been the introduction of HbA1c in the early eighties, and, of course, blood glucose monitoring. And these, in conjunction with all the other understandings of the metabolic control of diabetes, has led to a much greater interest in the condition, and a much bigger attention to looking after it medically.
- (22) One other aspect of children's diabetes that I have been privileged to be part of, in the last twenty years, is the International Society for Paediatric and Adolescent Diabetes. And as part of the sort of progress and change that has occurred over the last twenty years, we have published a set of standards and guidelines for the care of children with diabetes. And the one that I happened to be personally involved in very greatly, in the year 2000, was the Type 1 Diabetes Guidelines, which has been very heavily quoted in medical journals, and hopefully has improved - helped to improve - standards of care world-wide, particularly in some countries where the

provisions of care are far less than we have here in the UK. Secondly: ten years ago, a colleague of mine, in Copenhagen, set up an international study group, whereby about twenty two international collaborators have studied standards of care in children in our different centres, and shown, again, huge variations in the glycaemic outcome of children with diabetes throughout the world. And we're trying very hard to identify which areas of care are more helpful and successful in looking after children. One of the latest results, interestingly, is that those centres of care which make the targets of control very clear and understood, by parents and children, seem to be more successful. In other words, if, for instance, a centre says that we are all trying to achieve an HbA1c of 7%, and make that a very clear statement of intent, those centres do seem to be more successful. Whereas, those of us, perhaps, in the UK are a little bit more woolly about this, and say "oh, well, if you get it down below 9% or 8%, you're doing quite well", don't do so well. And so, I think we do have to look at standards of care world-wide, compare our results, and try and improve in everything we do. Now, I suppose this is looking at diabetes in its much, much wider context. If one comes back to the home situation.

- (23) There have been many example... no, I should say a few examples, in my career, where real tragedies have occurred in diabetes, which illustrate how very, very difficult, and indeed - to coin a term that I've used in public before - how diabolical diabetes can be, for children and parents. Certain tragedies can occur, quite unexpectedly, with very severe hypoglycaemic attacks, occurring in all echelons of society. Even if children are well controlled, occasionally they have severe hypos. I have to say that some tragedies have occurred more commonly in rather poorer sections of society, where the care of the parents hasn't been anywhere near optimal. But these tragedies, these... the damage to children that can occur with hypos, are, fortunately, rare. And I would have to say that I am immensely impressed at how brilliantly many parents and young people look after their diabetes. I have to stress, again, how very difficult diabetes is to look after, for young people. But so many parents and children are extremely positive; they look after the children brilliantly, and expend a huge amount of time and energy trying to be successful. And the vast majority of the children we look after, grow up into extremely mature, independent individuals, who do extremely well in their jobs and their friendships, and their lives in general. And one of the most positive things, I would say, that I've gained personally out of helping to look after children with diabetes, is to see some of these youngsters getting to know each other very well; developing friendships, which are lifelong; helping others with their diabetes as they grow up; and gaining tremendous success in their own lives - in their jobs, going to university, playing sport at a very high level - and doing very, very positive things. And this is obviously, at the end of the day, the most important result of one's interest in diabetes.