

38. Hans Csucsmi

(1) Tell me about your background.

Well, I was born in 1934 in Vienna, Austria. My father was... the proper title was a machine locksmith, but there's no other way of translating it - he was an engineer - and my mother was a housewife. During that period, Austria was involved in a civil war, if you like - the political parties were fighting in the streets - and that carried on until Hitler walked into Austria. So, that was my earliest memory. But my grandfather had a garden, and we used to go regularly to our grandparents, and that's where I first came across diabetes. My grandmother - mother's mother - she was a diabetic, and I was very small and I watched her injecting herself. And she was very concerned, because at that time injection were given in the thighs, and the thigh was very leathery and the skin had dried up, and she found it difficult to find a space. Now, shortly after that, the war began, and my grandmother had further difficulties, because the insulin - the prescribed insulin - was reduced because of the war effort, and so the whole diet had changed. Also, in those days, we didn't have these pens and fancy needles. They were quite thick needles, metal syringes, and, of course, they had to be boiled. Now, again, during the war, there was a limited amount of replacement needles, so they had to sharpen them on the domestic sharpening stone to make it more comfortable. My grandmother eventually died of a heart attack. The other family member was my father's sister, and she was similarly affected by the war, the reduction in insulin. And eventually she suffered from visual disturbances, and it went that bad that she couldn't distinguish any colours, and it was quite often you saw her with two different coloured shoes and, you know, and different stockings. And eventually she died of a heart attack. Now, that brings me to my mother. Again, in the post war areas, there were rationing of gas - gas was only available at certain times. And somehow my mother forgot to switch off the gas and got gas poisoning when it was switched on, without her knowing it had come on. And she was taken to hospital, and they diagnosed a very high sugar

(2) level. And they said to her "well, come back in six months time and we'll do a proper test". Well, of course, she didn't, because she was worried about having to go on insulin like her mother was. So, she carried on until she had another operation, and then she was confirmed a diabetic.

Roughly when was that?

That would be somewhere 1960 - around the '60s she had that operation. Now, she was put on tablets, and I think it's worth mentioning again that patients are not properly educated. She was put on tablets, and she was under the misapprehension "if I take an extra pill, I can have an extra cream cake", which obviously didn't work. Now, the other thing, which was quite common amongst patients at that time, there was no HbA1c test, so when they went for the blood test, it was just what it was like on that day. So, now, the routine was - everybody went on a strict diet the week before they went to the test, so that

they wouldn't have to go on insulin. Now, my mother was on tablets for about twenty years, but she was also a smoker and it affected the blood vessel at the back of her eye. And the specialist was getting desperate, because he was giving her treatment to cure that, and by smoking she annulled the treatment, if you like. And eventually her sight was seriously affected, and she found it very difficult to see. In the end, she went in a nursing home, and she developed some large ulcers on her feet, which they couldn't heal. And, if I can say fortunately, she died, because very shortly they would have had to amputate the feet, and that would have been terrible. And so, you know, she was eighty six when she died, and it was really a pleasant relief. And that's really my family experiences of diabetes at a very early age. So, you know, diabetes was always around me in one form or another, but, of course, I never thought it'll affect me, you know.

(3) Tell me about your childhood in Vienna.

Well, as I mentioned earlier on, my grandfather had an allotment - a garden - and we spent a lot of time there in the middle of the city. Now, during the war, the early years of the war didn't affect us at all, because the publicity - the propaganda, if you like - was "one year of war", and everyone believed it, and, you know. . . So far as my school was concerned - well, my local school was closed because the army occupied it, and I went to different school, and that was all right. 1942, believe it or not, I was grossly underweight, and I was sent to a place in Italy, which is now part of Yugoslavia, in Istria. And it was a sort of convent and the nuns looked after me, and so my education was interrupted. And then I came back, and in 1943 it was already becoming rather difficult - bombs were being dropped in the night, the occasional one - and there was an offer of going to Hungary as an evacuee. And my parents weren't too keen, but I was always one for going abroad and going to see the world, so I went to Hungary for six months. And I had a lovely time and my education continued, but because I was doing fairly well, I got private tuition from the teacher there. And when I came back, I went back in an ordinary secondary school, because the war, then, already had become very, very serious. And indeed while we were at school there were bomb alarms, and we, you know, either dashed out and run home, or - if the teacher didn't catch us and put us in the cellar - but the aim was to get home. So, then I did a short stretch with some friends outside Vienna in a school, and that didn't work out, so I came back to Vienna to the school. And by then I was coming up to ten years of age, obviously, and then the invasion came - the allied invasion. And we left Vienna hurriedly when the Russians came in, and we just. . . we went to some people, and that didn't work out, just on the outskirts of Vienna. And we carried on, and we just escaped the last bit as the Russians closed the circle around Vienna. And we stayed with some people in the Austrian Tyrols, so I had no education for about six months at all.

(4) When we came back - well, my father had disappeared; nobody knew where he was. He was never in the army, because he was an engineer, you see, and it was only in the last fortnight he was drafted! And anyway,

eventually... our home had disappeared. It was occupied by some... they said because we weren't there, it was the property of the Red Army, and they could allocate it to somebody. Obviously it was some communist people who got it, so we stayed with the auntie who had the diabetes! Eventually, I went back to the secondary school, and after couple of years - because I had a good school report - I was transferred to the grammar school. And I did the grammar school, and then I went to the Academy of Commerce. And it was rather difficult, financially, to keep up with it, so I found myself a job in the fashion house as a trainee, well, commercial assistant, management assistant. And I got my exams, and then... well, eventually I had... the people we stayed with in the Tyrols, they built a boarding house, and when I got my commercial diploma I used to go and do the books for a free holiday. And in that period I met some people from England, and we made friends, and they invited me for a holiday in 1954. And then in 1955 I decided to come to England. They were nurses at Rampton Hospital, and I felt I wanted to do this type of work, rather than work in a fashion house. And I couldn't go to Rampton, because it came under the Crown, you see, and as an alien, you couldn't serve in the Crown, so I finished up in Birmingham. So, that's really my background.

What attracted you about nursing in England?

Well, it goes back a long time, to my early youth, if you like. I was always interested in psychology and studying people's behaviour, and in Austria, at that time, the psychiatric services were very clinical: white bench, white lockers, and people were, well, just locked up. Now, when I saw what happened in Rampton, I thought, well, you know, there was the in-depth study by the staff of individual people and getting it down to the deeper mind, if you like, you know, beneath the surface. And that really interested me, and I thought I would like to do that sort of work. And that's why I eventually came to St Margaret's as a student nurse. Now, I think one interesting point is that in Austria, English is taught from about ten years on, but it was very basic school English. But with my Latin, I managed to get through my nursing exam very, very well, and, in fact, I sat my exam three months before I should have done! So, you know, it always makes my smile when people argue whether it's worthwhile to learn Latin. Well, in my case it certainly was!

And who funded your training over here?

Well, the hospital - I was an employee, I was a student nurse, resident at the hospital. At that time, there was rooms attached to the wards and, you know, I lived in a ward upstairs, with one of the chappies. We had a room each and we had board and lodging provided. My first monthly salary was nine pounds nineteen and eleven pence!

(5) And what year did you come to England?

1955. And again, we were talking about the weather - it was a beautiful sunny day, and I was sitting on deck of the channel ferry. And I stayed with

a friend for two weeks, and I came to St Margaret's on the thirtieth of January, and there was four foot of snow, and the man driving the taxi couldn't get on! So, within another week, it will be fifty years since I started my career at St Margaret's Hospital! May I say, at that time, St Margaret's was considered one of the best training schools in the country, and, you know, that's why my friends selected it for me, and I was fortunate to get it.

Were there many male nurses?

Oh, yes. In hospital it was fifty-fifty, because again it was still very institutional: there were a male side and a female side. And the males didn't have permission to go in the female side - only for a particular reason. And if we... there was only a television in the nurses home, and if we wanted to watch the television, we had to write to the matron and ask permission, 'cause it was out of bounds for men, you see!

What was the training like?

Well, the training - again, I'm very conventional, and that the training was excellent, because we were taught the basics, which started off with hygiene, anatomy and physiology. And the idea was that you couldn't really learn how things were unless you knew how they were composed of, so the anatomy was the first thing. And we did quite a bit of research in our time off - we were given projects to do and find out this and that and the other. And then, of course, there was the psychology and then the psychiatry. And it was very... it was textbook learning, but with the medical staff - we had a medical superintendent who was a brilliant man - and so there was excellent teaching, which has now changed, because people are now involved in project works and doing a lot of projects - which I will call 'Mickey Mouse' projects - because they don't really come to the root of the needs of the patient. But again, today it's to care in the community, and I've still got books upstairs where it classified the different types of mental handicap, which now is largely ignored, because the term learning disability glosses over the true problem. So, I feel that I had a far more thorough training. It was also, up until the prelim examination, it was the same as for general hospitals, so, you know, once you passed the exams in mental health, you get two year's credit - you got one year credit, and you could do the general training doing two years instead of three years. And, in fact, my prelim exam I sat at the Birmingham General Hospital with the general nurses, you know, and the second one I sat at the QE. So, you know, I think in those days there was a more in-depth training for nurses than there is now. But then again, we didn't have all the technical equipment to bother with. You know, today the nurses have to be trained to be able to operate most sophisticated equipment, which we didn't have. It was hands-on nursing and that was it.

(6) Did you come across any diabetes when you were nursing?

Oh, yes. Now, I'm still a little puzzled by this, because most of the patients suffering from diabetes - obviously they were mentally handicapped - were on

the TB ward. We had very... I can't remember having any male patients with diabetes on any of the other wards. I believe there was one or two females, but we had four on the TB ward. Now, whether the diabetes exposed them to infection or something, we will never know. Now, the problem was, obviously, some of these patients were of very low intellect, and they didn't know what happened to 'em. And we had to watch 'em, because they couldn't understand why they couldn't have the same food as other people. And the diets were very, very basic and everything had to be weighed. They were all on insulin, which was, again, the ordinary insulin and had to be given just before meals, three times a day. The Lente insulin only came out a little bit later. Now, then we had the tests. Now, basically, they were only urine tests, and we didn't have any strips or tablets to start with, so the urine had to be boiled with a Bunsen burner and all sorts of things; it was quite a performance to test the urine. Blood sugar tests were done in laboratory, but again, that was a lengthy process, and sometimes it took nearly two weeks before you got the result, so, you know, it was very basic. But then we got some tablets: the Clinitest tablets, and later the Clinistix, which made life easier. The most dramatic experience I had, when I worked in a general hospital on the medical ward, we obviously we got people admitted with hyper and hypoglycaemic comas. And one gentleman - I still remember him very clearly - he had both his legs amputated when he came in. And he was admitted with acute kidney failure, and he developed uremic fits. Now, I, that time, was perhaps the only one who recognised it, because most people thought it was an epileptic fit. But during my psychiatric training, we were taught that, you know, there's a difference between a uremic fit and an epileptic fit, and the only difference is that the people with the uremic fit are not incontinent, but otherwise it's exactly the same. And that poor chap eventually died from kidney failure, and that really, you know, indicated to me the serious side-effects from diabetes. But may I say, this is type one diabetes,

- (7) you know, he obviously suffered most of his life from diabetes, but the available treatment was perhaps not as sophisticated as it is now. After I retired from full-time working I got involved in quite a bit of voluntary work, and I was chairman of Walsall Community Health Council, and therefore volunteered for all sorts of bodies. One was the Long-Term Condition Alliance, which was a project for various long-term conditions, but Walsall was a diabetic one. And so, again, I was involved in several meetings, and we could talk to patients and their experiences. And I think that is worth noting, because people didn't get proper information about the condition. And one person bought a glucose meter, but nobody told him what it meant, and, of course, he was measuring his blood glucose at different times of the day, and he was up and down, up and down. And in the end, he chucked it in the bin, because he just didn't know what it meant and how he could use it to control his diabetes. Another problem we've found - later on I was chairman of the Diabetic Advisory Group to the Walsall Health Authority, and we tried to obviously improve the service to people suffering from diabetes. And we got contracts out on

the retinopathy, and we recruited more and more optometrists to do the treatment, and the Walsall Health Authority was paying. But we found, in particular the elderly, were reluctant to go and have the test, because they confused it with a vision test, and they couldn't afford to have new spectacles, and they were afraid that the opticians would pressurise them into having new spectacles. And it was very difficult to explain to those people that the two things were not connected, you know. So, we had all these contracts, but the uptake was rather slow. And the other difficult thing we had, we persuaded the Walsall Health Authority to pay for every newly diagnosed person diagnosed with diabetes a one year subscription for the Diabetes UK. And it went through the GPs, and the uptake was just disappointing, because people weren't told about it. So, you know, because we felt that this was a most efficient way of communicating to people, because GPs didn't always have the time or the knowledge to tell people. In Walsall, in particular, fifty percent of the GPs were single-handed, and so they didn't have practice nurses, you know. And we felt it was a good way of getting through to people, but unfortunately it didn't work.

- (8) Well, now, all that happened after you were retired. Let's go back to 1950s. You've arrived in England; you've trained at St Margaret's. Tell me what happened then.

Well, at that time my wife was training as well, and she was slightly ahead of myself, and she passed her exams before me. And when I passed mine... when she passed hers we decided we would get married, and we got a flat locally, and then I passed my exams. She continued to work at the hospital until she had my son. Then she stayed at home for eight years, and then eventually she came back.

How did you meet her?

Well, in the hospital, you know. In the training school you met up with people, and then we had a social club, which wasn't very elaborate - it was the patients' canteen - but at night we could use it! And there was no alcoholic licence, so any drinks we had to carry from the pub up the road! So, it was... well, it was very basic, but, you know, it was very pleasant, you know. There seemed to be a camaraderie amongst the nurses, you know, and everybody seemed to get on well. The wife went back to work, then, on nights, and I... well, I was promoted to charge nurse, and then to... we had the Salmon system coming in of management structure, which I still think was one of the best structures, and it was unfortunate that now it's no longer being used.

When was this?

1960, and again, St Margaret's was a pilot scheme for the Salmon structure. And I was appointed charge nurse on a rather difficult ward. It was... well, it was called the refractory ward. In fact what happened, most of the patients were court admissions and then quite a few were under Home Secretary restrictions. After that, I was promoted to a nursing officer, and I got four wards in the unit

to supervise. But I think it's notable to say that although you were appointed to a job, everybody had to do something on the side, like someone was responsible for the cadets, somebody was responsible for the student nurses, somebody was responsible for the adult education for the... you know, liaison with the adult education with the patients. So, you know, people did more just than the job, and that made the job more interesting, obviously. Well, shortly after then, in 1972,

- (9) I was promoted night manager of the hospital. And that was a completely new job - it was senior nursing officer: night duty. But previous to that, there was a night superintendent on the male side and a night superintendent on the female side, and my job was for the whole of the hospital. Also, it was meant to provide the liaison between day and night duty, which up until then were two different worlds. So, my job was, I used to go to work at six o'clock at night, stay till two or three, go home, go to bed, and back in the hospital at 9.10 in the morning to attend meetings, and then back again on duty at six o'clock at night. Now, that was a problem. I was eating day and night, and smoking day and night, and therefore I was grossly overweight, and... well, I was quite happy about that, until I took my dog for a walk one night and the street lights were like sparklers! And I... "oh", I thought, "that's funny". Well, then I found that in the day, one day I could see better long distance and not short distant, and the next day it was reversed. So, I thought "well, I better go to the doctor". And he said "well, let's have a urine sample", and he said "well, I better send you to the diabetic clinic to the Birmingham General Hospital". The consultant, then, was Dr Wright - very nice - and he put me on a diet. And I think, again, it's worth a comment, because during my experiences talking to people, I found such a variety of approaches. And some patients were put straight on tablets, without even trying a diet, and I always felt that going on tablets brings you closer to insulin. So, I was grateful for Dr Wright to put me on a diet. Now, as it happened, two months later, after having been on the night job for eight years, I was offered a staff post on day duty, which meant I got my own little office. And I stopped smoking the first week in January, because after the Christmas holidays I found this was a good time of doing it. Now, I was away from all the smokers, and obviously my diet, now, was very regulated, and I could follow the diet.

How did you give up smoking?

Pardon.

How did you give up smoking?

I just stopped. Now, obviously, like most people, you don't just decide smoking, you have

- (10) several goes, and I found that reducing doesn't work. If you don't smoke till four o'clock in the afternoon, you still smoke twenty cigarettes. I also

found that although people say you are addicted to the nicotine, the biggest problem was habit. You're driving the car and when you turn a certain corner, that's where you light up. And it became routine, and I think the most important thing was to break that routine. And that, as I said, changing the job and changing my whole environment, and at the same time, my wife used to smoke - not a lot - but she decided to stop as well. So, you know, there was support for either of us, from each of us, and... well, we managed it eventually, and I managed to lose quite a bit of weight as well.

Can you remember the details of the diet you were put on?

Well, it was just a low carbohydrate diet. And I did get a little bit upset with the dieticians - I mean, you're always against the dieticians - but I found that whenever I saw a dietician, they told me something different to what the one previously told me. And I always said, you know, "have you come out from a different training school?". Just an example: the first one said "have granary bread", and twelve months later they said "oh, you mustn't have granary bread, it's wholemeal bread you must have", you know. And I also read a research project about low fat margarines, and it sort of said that it's produced from oil and it goes through ten chemical processes to solidify it, and there's something stops behind in each process. And I decided "well, I like my unsalted butter, and I'll reduce it", and I still do that now. I have unsalted butter once a day in the morning with my, you know, bread roll or whatever I have, and that's what I carried on. Now, the problem was that I ate a lot of greens and low fat stuff, and then I was diagnosed... well, I had some rectal bleeding, and I went to the examination. I was diagnosed to have diverticular problem, and that, of course, affected my diet, because all the things I was eating before, I just couldn't eat now, and so...

When was that?

- (11) Well, I was diagnosed with diabetes in 1979, and the diverticular problem was diagnosed in 1992. And obviously, after that, it affected my weight, because I couldn't maintain the strict diet.

What kinds of things did diverticulitis ban you from eating?

Well, it wasn't banning anything. It's... you ate something and you find you're in pain or you started haemorrhaging, and so you gradually adjusted yourself to that. Now, in 1994, then, I took part in the Acarbose study. And again, when you take part in a study, you don't know whether you get the real thing or the placebo, but it did cause me considerable problem. I was distended, and, in fact, going on the bus upstairs I felt nauseated, but I carried on with the study until it ended five years later. But I did persuade Dr Wright not to keep me on it, because, as I said, it caused me considerable discomfort, and I'm sure I did have the real thing. And I couldn't really see any effects with the blood sugar, but there might have been, because it could have risen. So, then I joined another research project. In 2000 I joined the lipid study for diabetes, and that



went on for two years, till 2002. Unfortunately, for some reason, a lot of those studies lost the funding, and so my involvement with Dr Wright and the studies ended at the end of 2002. In 2000, I was also... my blood pressure started to rise, and I was put on Atenolol by Dr Wright, which brought it down pretty well. But again, I think it's worth mentioning that the norms have changed, and what was acceptable then is not acceptable now - we're always going a little bit lower. But that carried on for some times. 2002, my blood sugar went up to a fairly unacceptable level - well, above the norm - and Dr Wright put me on Metformin. And I usually get affected from November till March, and then everything seems to go wrong: my blood pressure rises, my blood sugar rises. And the GP doubled the dose, and then doubled the dose again, and it didn't really make much difference. So, when Dr Wright retired, he transferred me to Dr Roberts in Sandwell, and he reviewed my whole medication, and I'm now on a right cocktail of drugs. But my blood pressure is well within acceptable levels, and so is my blood sugar, and, you know, I manage to keep my diet reasonably well. But my cholesterol is high, so that's the next target - to try and reduce it, because I don't want to go on any more medication, and, you know. So, I have... when the nice weather starts then I'll do a bit more exercise. And the... I'm afraid the lettuce from the supermarket isn't the same as the one I grow in the garden, so, you know, in another couple of months, we'll really tackle that.

(12) So, can you summarise, then, how long were you controlling your diabetes with diet alone?

About twenty three years, but I think it needs to be said, towards the end, it gradually - the blood sugar level - rise gradually a bit every time. But, you know, I felt very, very grateful that I was able to stay on diet, rather than the doctor taking the easy way out and put me on tablets, because that, you know, meant I could live a fairly normal life, because once you've taken tablets - once you're taking tablets - it rules your life. You've got to eat when you take the tablet, and you can't just skip one lot and not take the tablets, or take the tablets and not eat. So, you know, with a diet-only, it was very comfortable.

So, what would you say was your secret to manage on diet alone for twenty three years?

Well, first of all - I met with different people during my work on the Community Health Council, and eventually, I think, there was a general consensus of opinion - it's not right to talk about a diabetic diet. What we should talk is about a healthy diet: to have adequate fruit, vegetable, and a balanced diet, and I think that was the secret. I forgot about the diabetic diet, and I'm back again to the dietician. I just tried to have a healthy diet, and I liked fruit, I liked vegetable, I don't eat a lot of meat - unfortunately all the meat I like is red meat - but I like fish and I ate a lot of fish. So, you know, basically a healthy diet, as is publicised at the moment, and forget about the diabetic diet.

Was it a very big change for you in 1979?

Well, it was, because, as I said, I used to have a meal before I went to work at

six o'clock at night, and have something to eat at work, and when you get home have something before I went to bed, and then when I got up I have something else, and then by the time I got home it was just lunchtime and I had something else. And I, you know, it was a complete change. But, as I said, by changing my job, it was easier to organise my life and the routine of my diet.

Had you had any thoughts, with all the diabetes in your family, that you might get diabetes?

Well, I mean, that's the thing, you know - professionals usually are the last people to recognise problems in themselves. It's easy to advise other people, you know, "over fifty, overweight, you just watch it", you know, but it never occurred to me! And I think it's probably, in fairness, that most of my family members were females who had diabetes, and none of the male members ever had diabetes, you know. So, my father died of a aortic embolism, and so, you know, he never had diabetes, so it didn't occur to me.

(13) Have you had any other complications associated with diabetes?

No. One of the things is the retinopathy - I make my own arrangements. I can still look after my feet and I don't have to go to a chiropodist, but, at the same time, these services were never offered to me. And, you know, I'm sure it happens to a lot of people. And because I was involved in all the different studies and project, and I'm aware, I make sure that I get my annual - or fifteen months is it now - retinopathy test, and, as I say, I don't need a chiropodist at the moment. But if I do, I would obviously make my own arrangements, and so I'm reducing the side-effects, if you like, or the possible hazards. I do get some muscular problems, like get the cramp in your legs about two o'clock in the morning, and again, by some of the knowledge, I go to the health shop and buy some magnesium tablets, which now I've reduced it to a minimum. But, you know, you can never really tell at my age - I'm seventy now - whether it's old age or diabetes. Things happen and you just accept them and say "oh well, it's old age", but, you know, I am aware of complications, obviously. My GP is very understanding. If I go and say I've got a problem, he deals with it very promptly.

How much contact do you have with your GP and with hospitals?

Well, the hospitals - I'm going every six months. My GP - well, there's a problem there. I got a GP thirty years ago and he retired, and I've gone to his son and he retired last year, and then I got over to his wife, and she retired six months later. So, I'm now with his senior partner, who's a very nice gentleman. And according to the rules, we have to have an annual review of repeat prescriptions. But when I go to the clinic, then obviously they send a letter, and I usually give it about six weeks and I pop in and we just discuss the letter from the consultant. Now, I did once go to the GP's diabetic clinic, and it was one of his partners, and I haven't been back since. They do keep inviting me, but basically all they did is what I do myself every week, and I felt it was just a waste of time going there. And really what I'm looking for is an annual proper blood test by a

laboratory, and I was promised that I would get that. And, as I say, I do my blood sugar and do my blood pressure regular, and I keep a record. And I think that is also important, to

- (14) have a random record of taking your blood sugar different times of the day and recording it, so at the end of the day, you know, there's a good view, or an overall view of the condition. And I'm very pleased to say that my random tests are very, very close to the HbA1c - there's very little difference - so I'm pleased, you know, with that. I think a lot of the diabetics, they think that they... well, they're misleading the doctors. Well, they're misleading themselves, and you've got to be honest with yourself, and say "well, that's my problem, that's the condition's going worse and I've got to do something about it", not hide it and say "oh, I'm all right, Doctor" you know, "don't put me on insulin". But sooner or later you might have to go on insulin, you know.

How did you test your blood sugars when you were first diagnosed?

Immediately with strips, because all the testing equipment just came out then. And at the same time, fortunately, the NHS also started to pay for the strips, so, you know, I did the blood test myself straight away. Of course, I've got now improved meters - things a lot easier now. And I still do urine tests as well. And it's quite interesting, because last year - early last year - when my blood sugar rose, I also got sugar in the urine. Now, since the treatment was changed then it's all gone, you know. So, you know, it is important to do the two and compare the results.

Now, you've seen the relationship between patient and medical staff from both sides of the fence, as it were. How do you think relationships have changed over your lifetime between patients and medical staff?

Well, the difficulty is with the GPs, and in all fairness to the GPs, you can't be an expert in everything. There's arguments about electronic recording and the question's always "who's going to pay for it?". And so, some GPs, obviously, are experts in heart conditions and something else, and then others take a specific interest in diabetes. So, it's a bit of a lottery, for the patients, what support they get. They've also got the practice nurses, and some of them are very good and very helpful, some good community service, and others haven't, so, you know. And the Diabetic Advisory Group I was chairing for four years, we work very hard

- (15) to bring the different branches of the services together, but in the last eighteen months we've found no GP attended our meetings - you know, it was the wrong day, the wrong time. But we did manage to get funding for handheld records for children, so that the parents had records for the children, and we published quite a lot of information leaflet for newly diagnosed patients. But it all seems to be isolated pockets. Now, when we got the new Primary Care Trust, Health Authorities were abolished. Every five years the Health Service is reorganised, and all the work that's

being done seems to disappear. At the end of the Health Authority, I was a member of the National Service Framework Implementation Group for Diabetes. We haven't met for three years, because the new Primary Care Trust took over, and they haven't picked up the thread yet of the work that's been done. In fact, I'm sure they don't even think about it; it's forgotten, you know. We used to have the Health Authority - the community physicians. They had specialists: registrars and consultant that took special interest in diabetes and other conditions, and, of course, that's disappeared now. So, you know, we keep on fighting, we keep on asking awkward questions!

And what about the actual way that medical staff relate to patients. Do you think that's changed over the years?

Well, again, you know, there's several problem, where we're having the move to Primary Care. And again, it's the knowledge and the education of the GPs, and who pays for it and what is available. And again, some of the GPs are excellent and have plenty of information - they produce their own leaflets and so on. But so far as I'm concerned, my main source of information is the UK diabetes journal, the Balance. That's where I get my information from, you know, because I get nothing from the doctor. I suppose if I went to the clinic, but the last time I went they didn't tell me anything, you know, they just weighed me and did the strip test, the blood sugar, like I do... You see, from the word go, I do my blood sugar first thing every Sunday morning, and my blood pressure. It's exactly the same condition

- (16) every time I do it. When I get up on Sunday, I'll do my blood sugar, and that's why I've been able to monitor it, because I didn't vary the condition. I do it in between as well to get the random, but the basic, you know, test is first thing, a fasting blood sugar, every Sunday morning.

Can you describe a typical day in your life now, and go right through the day, including this cocktail of drugs that you mentioned?

Well, I can't, because for the past thirty years I've been a member of the Birmingham Employment Tribunals, and last year we were really hectic, and I was having twenty three day cases. And so my diet went... I just managed to take tablets and the sandwich in the breaks. Now, in October, having reached the age of seventy, I could no longer continue, but I still continue on part-heard cases, and I've got two or three coming up in the next few month. So, you know, there wasn't a proper routine, because I was very close to the offices and they would quite often ring me up at short notice and say "can you come now?", you know, so... But now I'm establishing a proper routine - you know, I'll get up at the same time, I'll have my lunch at the same time, I'll have my evening snack at the same time, and hopefully, you know, it will help to reduce my cholesterol. But, as I say, last year it was top-side down, and then my wife's illness, obviously - going to the hospital every day. And one place she was, was twenty two miles from here, so that affected my whole regime. But, as I say, I hope within the

next few months I'll get myself sorted out.

Was your wife involved in controlling your diet?

Not at all. Because I worked night duty, she worked day duty, my son was always very good and cooking his own stuff - he always used to go out somewhere, have a meal, and then come home and experiment and so on - so we all really looked after ourselves over the years, and that continued, you know. And again, the preferences, because she obviously wouldn't always eat what I ate. The only real common meal was on Sundays, you know, and then we forgot about the diet, and I had my glass of wine with my Sunday lunch, and I still do.

And what's this cocktail of drugs that you're on?

Well, I'm on the Metformin, and control the blood pressure.

- (17) Well, you know, I'm on all the... Metformin I'm on three times a day, then I'm on Pioglitazone, which I take lunchtime, Bendrofluazide in the morning, and Atenolol. Because of my diverticular problem I take a Regulan or similar compounds twice a day. Self-medication - I use some magnesium to counteract the cramps I used to get, and that's... and now... you see I had... one problem was that my blood pressure was well-controlled during the day, but first thing in the morning it was always up, so I was put on a Zestoretic at night, and that seemed to have lowered it, you know, in the morning. It's still a bit up in the morning, but it's within acceptable limits. And I don't know why one morning it's up higher than another, but probably if you have nightmares or a dream or something, I don't know! So that's roughly what I'm on at the moment.

And how much exercise do you get on average?

Well, first thing, before I have my breakfast, I take the dog for a walk for about quarter of an hour, and she goes two or three times a day. Now, I live very close to shops and the bank, so, you know, I always walk down, which is about quarter of a mile, so, you know, I do at least a mile, a minimum of a mile. And being fortunate to have a bus pass, the car stops in the garage whenever, you know, I can do without it, so again, there's a lot of exercise. And in the summer, I do a lot of gardening, obviously. I'm out there - I'm always doing something.

What keeps you going?

Well, a friend of mine always says "life is mind over matter - we don't mind and you don't matter!", and I think that keeps me going! I also, I was sixty eight when I got a City & Guild in Computer Applications. I went to Walsall College and did the computer application course, because, you know, over sixty, Walsall College lets you have free courses. So, you see, up until two years ago, I was honorary administrator of the British Society for Developmental Disabilities, and, of course, I used to deal with subscribers all over the world, and, you know, I got faxes at three o'clock in the morning from Taiwan. I also, you know, was secretary of the League of Friends of St Margaret's Hospital, which we now close.

Well, at the moment I'm chairman of Age Concern, Walsall, which again keeps me going, and, you know, it

(18) keeps my social contact going.

This is a difficult question to answer, as your wife has just died, but how do you see the future, particularly with regard to diabetes?

Again, at my age, I think it's best to take every day as it comes, because if you plan too far ahead, you might get disappointed. You sort your life out. So far as the domestic arrangements, I've got to rearrange the whole household to make it convenient for me to cope with the demands of the household, you know, because she did her job and I did my job, and so on. Now, I've got to do it all, so, you know, we've got to reduce the volume as best as we can. But other than that, I don't make any long-term plans, now, what I'm going to do, because, you know, you never know what's going to happen.

Looking back, do you think your life would have been different, in any way, if you hadn't had diabetes?

No, because, you know, I... again, it's the awareness, and once you're fully aware and you... you've got the will to cope with it. We always said - diabetes is not an illness, it's a way of life. It stays with you, and it's the... the side-effects are illnesses, if you like, but the diabetes itself, it's just a problem you've got to live with, and you've got to adjust your life accordingly.

So, what would your message be to someone now, newly diagnosed with type two diabetes?

Well, first of all, you do a check of your life, and say "well", you know, "what can I do to reduce the problem and still live a comfortable life?". And like I said, when I was on the strict diet, I still had my ordinary Sunday lunch, because if you're on a diet seven days a week, eventually you say "oh", you know, "I won't carry on with this lot", and then... But if you have a nice Sunday lunch and your glass of wine, or whatever you have, you're ready to carry on with the diet on Monday. And I think people have to plan their life in that way to reduce the risk of the side-effects, because diabetes - the side-effects are the real problem. And, you know, my mother's - when she lived in Vienna - next-door neighbour, he had both his legs amputated, and he was living on the fourth floor and no lift, you know, and things like that. You have to make sure that you look after yourself, without interfering with your life too much, and it's quite easy to do.