

62. Mary MacKinnon

(1) Tell me about your background.

Well, I guess it's a fairly unusual one, in that my father was in the army, and my mother went with him, wherever he was posted. So, I've spent a great deal of my life abroad, and actually learnt to read in another language, because I was sent to an Italian school in Trieste. And I was sent there. My older brother was sent home to England to boarding school, because that was what happened, if you were an army child, whereas the daughters usually stayed with their parents. And so, all in all, I spent a lot of time in Italy and France, Germany, Malaya, and various other places, and went to eleven schools, altogether, which made for quite an interesting education. And I ended up going to a small boarding school, because I just had to complete my education, as I'd decided that I wanted to train to be a nurse, and I therefore had to have the right qualifications to apply. And because I was always changing curricula, it had been quite difficult to get to the right standard for the exams. So, basically that's the background that I've had: living abroad and then coming back to this country, and changing schools constantly.

Was your father an officer?

Yes, he was, yes. He was an officer in a regiment that's long ago defunct. It was merged with another regiment, and now it's disappeared in the mists of time. And after his regimental duties, he went into the Ministry of Defence, and he worked with Lord Mountbatten. And he was involved, crucially, in the Suez crisis, which was very interesting. And after that, when he left the army, he went in to become a company secretary.

And what made you want to become a nurse?

I think... We have a very medical family - mainly on, well, my side, and on my husband's side. But at the time, they were all doctors, and going back for several generations. And I wanted to be a nurse, I think, because my mother had a lot of ill health, I think partly due to the army life. But she was always very well looked after at a hospital in London, and it made me think "well, yes, I would like to do that. I would like to look after people, and make sure they got the right sort of care when they were ill". And so, that's really what made me decide, from quite a young age, actually.

(2) And tell me about your training.

Well, I'd applied to train in two hospitals in London; one was the Middlesex Hospital, and that's now gone. The other was St George's Hospital, which still exists. And the reason I chose St George's was because it was the one that my mother was so well looked after in, and the Middlesex was the one that my brother went to. And I decided that actually it would be... I'd probably have a better time if I went to the other hospital, so I accepted that one. And I did the conventional training, of the time. That would have been 1964, that I embarked on that training, and it was a three year course for, as it was, State Registered

Nurse, at that time. And it was a wonderful training school, with a very good reputation. And we got lots of experience, either working at the hospital at Hyde Park Corner, as it was then, and then also down at Tooting, which had been a famous fever hospital many years before. And so, it was a good training. And I qualified in 1967, and then spent a year as a staff nurse on a medical ward, which was for diabetes, endocrinology and metabolism, and that was an extremely useful year. We had, at George's, to do four years, before you could get your hospital certificate and your buckle, as they called it. And the reason, I think, was, it prolonged the training, actually, because you really started to learn your nursing after you'd finished training. And I think it was a very good principle.

For somebody training now, in 2007, can you summarise what the differences were?

Well, of course, the whole system's changed so much, now. You know, you're either a care assistant and you train through the non-vocational qualification system, or you do nursing as a degree subject. And I think one of the difficulties with this is that nursing is - I think like medicine - it should be an apprenticeship. And, of course, the minute you put it in as an academic subject, the apprenticeship side goes. And what we find - I've had a little experience of working with these nurses trained in the modern way - is that they actually, once they're qualified, know very little about real nursing. They know the theory, and they've done the sort of academic side, but so much of it is practical, and you don't learn it from books.

(3) So, perhaps some more detail about what it was like.

About the actual training. The training, at that time, was very well organised, certainly in the hospital that I was in. You had two months, or so, of preliminary training... it may have been three months of preliminary training school; PTS, it was called. And then you were launched onto the wards, with a certain amount of supervision, but not a huge amount, because the supervision was then taken over by the ward sister, in those days. And I did most of my training at Tooting, and this was the old fever hospital, and it had long Nightingale wards. You'd have twenty six, twenty seven patients in them. And you walked up and down those wards, and it was very, very tiring at the end of, you know, an eight or nine hour period. And they were open wards, just with curtains between the beds, and old-fashioned buildings, and it was very, very hard work indeed. And you had to fill in a book with your... having achieved certain procedures for the first time. And a staff nurse would supervise you, and then you would, as it were, take it as a test, and then you'd have it signed up in your book. You know, might be doing your first dressing or your first injection. And certainly, I can remember being very worried about giving injections, because the equipment we used was... were glass and metal syringes and needles. And they all had to be boiled, and you picked the needles out of the steriliser and looked at them, because very often they were barbed at the end. And you imagine giving this to a... an injection to a patient with a barbed needle was not very nice. So,

the injection technique was taught on an orange, in the training school, and then came the day of your first injection. And you picked up the syringe and the needle with some Cheatle's forceps, and you'd put them in a metal casing with a lid on it, that had also been sterilised. And there was a piece of cotton wool - a dry cotton wool - and a piece of cotton wool with spirit on it, and you would then take that, with the medicine card, to the bedside of the patient. And that's, basically, the sort of procedure that you would be signed up for. And, obviously, they got more and more complicated as you did more and more important procedures. And so, everything you did was checked. And so, it was really very rigorous, and you didn't get signed up if you weren't competent. And I think finding out about competency,

- (4) in a practical way, is very important. You know, you can learn the theory of doing something in a book, but you can't... you have to learn the practice of it, and its application to the care of patients. I think we used to nurse people, for instance, who came in in diabetic ketoacidosis. I very rarely saw a well person with diabetes, in those days. My experience was almost entirely of people admitted in an emergency situation, who were in a coma. And we would have them - quite often, six of those - at the beginning... the first part of the ward, which was where the more acute patients were nursed, and you would have six or seven on respirators. And they weren't in an intensive care unit; they were on an ordinary ward, and they were on these machines, because they couldn't breathe themselves. And you might be allocated to look after two, two or three of those, and that was what your job was. And, obviously, you had to be fairly senior to do that work. And it's interesting: I mean, I don't think you'd nurse people like that on a medical ward now, and we took that as completely normal.

Were they in a coma because they hadn't been diagnosed with diabetes, or because something had gone wrong?

I think both situations. The diagnosis was missed, or, I mean, the self-management of diabetes may have been poor, or they may have had an inter-current illness which tipped them over. And, of course, we didn't have blood glucose monitoring, in those days. Everything was done by urine testing, using tablets - Clinitest tablets - and so on, and it was very imprecise. So, if patients were testing their own urine, they would not be able to gauge whether things were going much worse than the very worse, because they were using urine testing tablets; if they got them at all.

- (5) And tell me about insulin in the 1960s.

Well, everybody used to - well the nurses, especially the more junior ones - used to dread it when someone with diabetes came in, because - came into hospital - because then it meant, of course, they would be giving insulin. And in those days, it was in a very different form. We didn't have hundred unit insulin, in those days; it was twenty, forty, eighty insulin. And so, therefore, you had to

work out what the dose was, because of the concentration of the insulins that were used. And it wasn't uncommon - I wouldn't say very often - but it wasn't uncommon for mistakes to be made, and it was something we all dreaded. And so, to cover our backs, we used to make sure that we had two people check it out every time. It did make for complications. I think, probably, the mistakes were less than they might have been now, because in those days, you did have a very constant workforce. You didn't have people coming from agencies to nurse patients on the ward, who didn't know the ropes and didn't know the patients. We did used to have a very constant workforce. We worked for... there were "X" number of nurses for the ward, there was a rota done, and you did seven nights on and four off, and then you went on to days for the rest of the month, and so on. So, night and day, you had a constant workforce. And from the point of view of patients, the continuity of care, I think it was wonderful, that system. And I think they were able to retain staff, because we had a very, very strong hospital... the value of nursing and nurses was very high. And every day, the matron, or an assistant matron, came round; they spoke to you personally; they would roll their sleeves up if there were people off sick, they would roll their sleeves up and actually come and help, you know, if the staff were short. And I think it's about feeling... we felt very proud of the ward we were on, and very proud of the hospital we were in, and I think that makes for good patient care.

And with regard to diabetes, what are your most vivid memories from the 1960s?

I think what I remember is the... how sick, and how very, very ill the people were, who were admitted to hospital. I didn't see much of those who attended outpatient clinics. I wasn't involved, really, at all in their management or follow-up, but looking after them when they were very ill. And they usually were very, very ill, and very often died, because they were in such a bad state when they came in. And the knowledge of the physiology and the corrective treatment was - although it was good - was, of course, nothing like it is today. So, what I'd say is, you know, that severe diabetes, and diabetes with its acute complications, was often a death sentence, and that's probably the thing that hits me most.

(6) What did you do after your training ended?

Well, having... I first of all completed my year in the diabetes and general medicine ward at St George's, and then got married, and we went to live in Hastings. And my husband was a surgeon, so he got on with that, and I sort of made our first home. And then was called by someone from the hospital, who knew that I'd recently qualified, and asked me if I would consider applying for a job that was coming up, which was working in a ward, which was really very, very revolutionary at the time. It was an orthopaedic surgeon who devised a system of operating on elderly people who'd fractured their hips, and they... he would rehabilitate them, and they would be up and walking the next day. And, at the time, this was absolutely astonishing. Every person had their own wardrobe and dressing table; they were up and dressed. He didn't want them being sick and getting ill and complications; he wanted to get them home as soon as possible. So, it was a fantastic ward to work in, with a very unusual surgeon.

And then, they wanted... the ward, actually, wasn't safe, in terms of the staff working on it, to do acute surgery - general surgery - and they needed some beds opening on this ward. So, my job was to go and make it a safe place for general surgical patients, as well as lifting the standard of what was there already. They had quite good staff, but they had been there a long time, and they weren't desperately well-educated, in terms of keeping up to date, and I think that's really what the problem was. So, it was a matter of getting something going. And it was very interesting doing something completely different to medicine. And after that, I moved and had a career break, and that's when we had our family. So, that was a very interesting period of my life, as well; probably the best thing I ever did!

How long was the career break?

That was ten years.

And what did you do after your career break?

Well, I... by this time, we'd moved to Sheffield, and this was going to be our final move. And so I thought, "well, I'll go and work in operating theatres", because, having had a break, at least, you know, I can pick that up in a lowly fashion, and won't have too much responsibility, because I've been away from it, and the patients will all be unconscious. So, I was there for a very short time, working the hours I wanted to, because, of course, by this time, I had an elderly person living here, and two small... two young children. So, I was getting quite busy. And then, after that... that stopped, because my husband slipped a disc. And he... I was called home, and I called out the general practitioner, locally. And he and I, while we were dragging my husband across the floor on a mattress, because he couldn't move, and he was... the morphine he'd been given was taking effect, the GP asked me if I'd like a job. And that's actually what happened. And he said "well, when your husband's better and things have settled down, come down to the surgery and see me". And that was really the start of my career.

(7) Tell me about the job in the GP's surgery.

Well, this would have been 1979, and this was a practice nurse job. They had had someone there before, doing general practice nursing, and a little bit of diabetes, as there'd been a research nurse going around Sheffield setting up some clinics, because, as a research exercise, a thousand patients were discharged from diabetic clinics, in the hospitals, to their GP. And then there was a paper written as to the results of this exercise. So, there had been a little bit of diabetes work done in this surgery, but it was fairly minimal. And, of course, working in general practice is very different from working in a hospital, and so I had an awful lot to learn. I was faintly horrified to find that, when I got there, that instruments were boiled up in saucepans, and they quite enjoyed doing a little bit of minor surgery, and there was quite a lot of prescribing, actually, from within the practice... dispensing, rather. And so, it was a completely new world. It was doing things like dressings, travel protection, vaccinations, baby clinics, diabetic

clinic, hypertension clinics; really, a very busy job indeed. And with a practice... it was a practice that had a main surgery, with a very mixed population of Asian people and white people, and a Polish population - several of whom had actually survived Auschwitz, and they were very special, those patients. And then there was a branch surgery in another part of Sheffield, a little further out, which had a completely different middle class, white, affluent population. So, it was very interesting. And I mainly... I worked one day a week at the branch surgery, and the rest of the time at the main surgery. And this was a part-time job, but it felt like it wasn't part-time. There was just me, as the one nurse, with about four partners, and several very good receptionists. There was just one that was a little bit awkward at times. And I had an interesting place, which I had to learn about, where I was in this... it was a small organisation, it was a business. We also had a practice manager. But, on the whole, a very happy practice. It was also a training practice for GPs, which made it interesting too.

- (8) How common was it to have a practice nurse and a practice manager, in 1979, 1980?

Practice nursing, practice managers, really, were in their infancy, at that point. And it wasn't very long... I would have said I'd been in the job about a year, maybe two years, when I realised how isolated you could be, as a nurse. And I set about working... trying to work out how many practice nurses there were in Sheffield, and wrote to them all and suggested we had a group, and set up a group. And I'm pleased to say that's still there, and flourishing, today. And, in fact, Sheffield, in 2007, will host the National Practice Nurses Conference for the second time. So, it was very, very early days. And I remember the first practice nurses' meeting; there would have been about twelve people. And we had a dermatologist come and talk to us about looking after venous ulcers, which were a big problem that practice nurses had to deal with, at the time - patients coming to have their dressings and treatment done at the surgery. So, practice nursing was new, and so was prac... practice managers were fairly new - I would have said slightly less new than nurses. But, of course, general practice is a business, and the practice manager really had a very responsible job to do. And it was an important role that has obviously been developed hugely since then. But, I think it came home to me, one day, about practice nursing being a business - a very important lesson that I learnt, before developing my career in diabetes. And I was hauled over the coals, by the GPs, for costing them a lot of money, in terms of buying dressings and so on, to deal with whatever I had to deal with, because there'd been nothing there. I mean, there was just nothing there when I went there, and, in fact, it wasn't even very clean. So, I had to put into principles... put into practice, principles I had learnt about - you know, cleanliness and disinfection, and all that kind of thing - into this organisation. So, I did a little research exercise, and I actually wrote down every single thing I did, everything I bought. I got it checked with a pharmacist, from whom I bought all the items, and I worked it out. I then set it down on paper, and asked to meet with the GPs, which wasn't a regular occurrence, at that time. Generally, the GPs had their own little meetings, and I wasn't included.

Anyway, I then presented to them the results of this exercise, and it worked out

- (9) that I had spent a penny on each patient. And they never questioned my judgement again. But it did teach me that you actually have to think in terms of business, when you're thinking about general practice, because that's what it is.

You mentioned that before you became a practice nurse, there had been this research exercise discharging people from the hospitals. Did this mean that your patients with diabetes were just coming to you, or...?

Right, that was... the research, where a thousand patients were discharged, was, as it were, a discreet project; it was a properly conducted research programme. A thousand patients were discharged, and, of course, the result of that was that many of them thought they'd been cured, because, again, this whole thing about communication and education just wasn't there, at that time. And so we had, in the practice, I started to look at the diabetes, because I'd always been interested in it, since that ward long ago, and there had been a little bit done. They had... they did have a dedicated session for diabetes - they'd got that going. But, at that time, there were a lot of people not diagnosed; they didn't have a register - proper register; they didn't have the items, you know, educational things for patients; they didn't have a dedicated protocol. It was just, you know, seeing some patients, and if they had problems then I would refer them to the GP. So, I set to work, really, to start putting this into an efficient, organised session. And I also was worried about the number of people who we knew about, but didn't come to this clinic, or couldn't come. Because we identified, I should think, probably it would have been under 2%, which would have been about right for that time, that you would have identified that number, knowing there were another 1 to 2% around undiagnosed. So, I asked the doctors if I could have one day a... one session a month, in my car, visiting people to give them a check-up; a sort of annual review. And they agreed to that, and would follow up if I asked them to. A doctor would go if this person had... it was identified they had a foot problem, or they had other medical problems. So, actually, it was a very flexible service, which dealt with people who couldn't come to the surgery, or couldn't come to the branch surgery. We could see people at home, so it was really quite forward thinking, I think, at the time.

What kind of people came to your diabetes clinic?

Well, they would be generally people with Type 2 diabetes. Once I'd got all the notes out, and started looking through them, which is what I had to do to set up the register, and start picking up people who hadn't been diagnosed. The people with Type 1 diabetes, historically, had virtually always gone to the adult clinics in Sheffield; the two main hospitals. And then the other category, of course, would be the children, and they, historically, had always gone to the Children's Hospital, or they used to have a clinic at the Northern General. So actually, provision for Type 1 diabetes and children with diabetes was very good, so we didn't have to worry too much about those people, because we knew they were

getting looked after. But if they... not infrequently, once the diabetic clinic was really well established, people with Type 1 diabetes would ring up and come down, and say, you know, "I've got a bit of a problem about something". So, we did see them occasionally.

- (10) To what extent were you specialising in diabetes, during this period 1980 to 1985, as a practice nurse?

Certainly, the beginning of this five year period, I wouldn't have said I was. I was busy learning about general practice and all about it, and trying to develop a good service to patients. But my interests in diabetes did increase, and we got more and more patients, so that it became a very big clinic. And it was at that point, I thought I really needed - especially having had a career break, and so on - I needed to learn more myself, and get involved more. So, I went up to the Hallamshire Hospital, and, in fact, got involved with Professor John Ward's unit; and he was very helpful. And I told him what we were doing. I even asked him to come out with me and meet the general practitioners, because clearly there was something really important about good diabetes care, and in general, the GPs had been fairly dismissive of hospital diabetologists. In other words, I could see this huge chasm between general practice and hospital diabetes care. But, at the same time - and we're looking at around 1983, or so - a psychologist, Clare Bradley, was working in Sheffield, actually with Professor Ward. And she started to talk about: let's do some work with people with diabetes - in the hospital, mainly - in groups. And I got involved, as a member of that team, because I could fit it in with my other work, and so we started running group education sessions. These were structured, and the best bit was having lunch with everybody. The dietary bit wasn't done as a talk; we all sat down and had lunch together. And most of the issues, surrounding diet, were dealt with in the conversation over lunch, which was quite a nice way of doing it, I think. So, I got very interested in diabetes. I got involved with the researchers, and involved with the beginnings of our education programmes in Sheffield. And then, I had the opportunity to go on - as one of the first groups of nurses - to the very first diabetes training programme in the country. And that was actually developed by someone called Janet Kinson, who's a very well-known nurse - there's a named lecture after her - and she was very inspiring. And a lot of the sort of old lags of us, in diabetes, were on that programme. And so, that was a key point, really, because it made me realise: yes, I did want to do more in diabetes. I had to make a decision, at the end of five years. Would I stay in the practice and carry on, or would I do something else? And I had this sort of idea that: wouldn't it be great to go around all the general practices in Sheffield. I had links with many of them, because I had set up a practice nurses' group. And I would actually do a semi-structured interview with the general practitioner, in that practice, and do this as a research project: find out what they do and why they do it, what services is there to patients. Remember, going back to those thousand people who were discharged, who thought they were cured: what actually was needed was a service in general practice for people with diabetes, but did they actually get it? And so, that's what I set out to do. So, I resigned from the practice; a



very happy five years. And having put forward this idea, and supported by John Ward, we applied to Servier for a grant, and they gave a grant for three years to do this work. And it was completed on time, and written up in the British Medical Journal.

- (11) I'd like to back-track to ask two questions. First of all, why were the GPs dismissive of hospital consultants, regarding diabetes?

I think it was because they were, sort of, in ivory towers. They were the specialists, they were the experts, and I guess were pretty dismissive of general practice. They really didn't think... the consultants didn't think that general practitioners could look after people with diabetes at all. And, of course, what we're seeing here was the development of a specialty. And naturally, the doctors in hospitals wanted to establish their territory, their research, and so on, and, therefore, they were the experts; and one can understand that side of it too. So, there was a chasm, because GPs thought they could do quite a good job with people with diabetes, and look after them. Specialists thought they could do a very good job. And, of course, then that was really turf wars time.

And you mentioned a specialist course that you went on in 1983. Can you tell me more about that?

Yes, this was a fairly new venture; it was called "Specialising in Diabetes for Nurses". These weren't people who were deemed as specialist nurses, in that time. They were general nurses, but they did have an interest in diabetes, and were looking to gain expertise in the subject. And it was a three or four day course, as far as I remember. Very intensive: first thing in the morning, until quite late in the evening. And it was monitored; it was... there were several well-known people both on it, and looking after it. And it took place in Birmingham. It was a... Janet Kinson, who ran it, was, in fact, a nurse tutor herself, who had got involved with some of the clinical work in the outpatients in Birmingham. And I think it was probably the understanding of what people with diabetes need, and the understanding that nurses, in particular, weren't able, really, to provide for that need, that she decided that something needed to be done. There needed to be education of professional nurses, in order that people with diabetes, also, were able to learn more about their condition. So, this course, in Birmingham, run by Janet Kinson, was inspirational, not only to me, but also to many other people. And I think the education of nurses - who were then, really, lead the way in the specialism of diabetes - and the advent of blood glucose monitoring, and, of course, the U100 insulins, were really very important in the progress of the care of people with diabetes in this country. So, the 1980s was a very, very important time.

- (12) And what were the most important things you learnt from your three years of research, '85 to '88, going round to general practitioners?

Well, I think the first thing to say is, I made a lot friends; I hope I didn't make any enemies. But it did mean getting in my car with some nice things, and booklets, and interesting things, which I could take to general practitioners. And

very often, practices are hungry for that sort of thing. They need things for their patients; they don't always get them so easily as diabetic teams do. Is that they really want to be loved, and to go into a room and ask a GP about their family and children, and what their life is like. It's very important. And I learnt an awful lot that, you know, people's expectations of a general practitioner are pretty high. And in those days - I'm not so sure it's true now - they were absolutely committed and dedicated to their patients, on the whole. There were, of course, some general practitioners who I was extremely concerned about what was going on. And so, I learnt a lot about standards: where there were appropriate standards of care, and where there were certainly inappropriate standards of care. And I also learnt about the business side, as I've already mentioned, of general practice, and how to use that to good advantage. For instance, like saying that if people employed a practice nurse - which is what I started off by doing - if they employed a practice nurse, they could actually make quite a lot of money. They could also make money if they ran a diabetes clinic. But I had to have all this prepared beforehand. So, I had to appeal to the nature of the general practitioner, and understand the culture of the practice, and also the hierarchy within it, because it's a mini-organisation, which can go very wrong if people don't get on with each other. So, it was very interesting learning all about the different cultures of general practice in the city.

How could they make money out of running a diabetes clinic?

Well, for a start, once you've identified people with diabetes in a practice, they're a captive population. And very often, they're older people, because they're older and they've got Type 2 diabetes, and they may have other medical problems. If you employ a practice nurse, and clearly there's an outgoing from that point of view, you can actually make money on all the different items of service that are provided. Certainly in those days you could - I think, to some extent, if not more so, now. For instance, if you're giving a 'flu... if we were giving 'flu jabs, they got... the GP would get paid for each one, and you filled a form in. So, employing a practice nurse, and having a designated group of people with a medical condition, you could actually make quite a lot of money, just through doing those two things.

(13) What did you do after you completed your three years research?

Well, I really wanted to get into and work in diabetes full-time, as a specialist nurse. And, in a way, I'd been doing specialist nursing, in a research sense, for three years, although I hadn't had my own patient load; I wasn't employed as such. But basically, was very keen to bridge the gaps in the city. And a co-ordinator's job - a diabetes nurse specialist co-ordinator's job - came up, and I applied for it and was successful. And so, I had the job of - as a diabetes nurse of my own patient load - of working across the city, working in specialist and primary care. And the other side of it was, slightly after that, I was very keen to set up a proper training for nursing in diabetes, with our school of nursing, as it was then. It's now a university department, but, at that time, it was a college of nursing. And this was to set up English National Board courses in diabetes,

which were available at that time - they'd become available. It was the ENB928 in Diabetes Nursing, and later on we also were able to put on a diploma level course in Sheffield - because I could see that we could improve patient care. But if we wanted to develop nursing, in terms of nurses in general practice knowing about diabetes, and also community nurses - but also to grow specialist nurses in the future - we certainly had to have a specialist training programme, which was nationally approved. So, my job was actually split between working for the university, to develop the programme and run it, and also my clinical load, and co-ordinating diabetes services across the city. And at that time, when I was first appointed, I was based at the Northern General Hospital. And very soon we had a diabetes centre there, because the consultant, Dr Colin Hardisty, had worked really hard to get this building. And it was actually... we had no staff, nobody there - just myself and another nurse, who was appointed after me. And the only way I could run a diabetes centre, which was the first one in the city, was I appointed and trained women from the Women's Royal Voluntary Service, who did it as a voluntary job. We paid their expenses, and it was really successful. They provided secretarial and tender loving care services; they looked after the stationery and all the supplies; and they did it in their own time, for nothing. But that was because there was no other way of doing it.

(14) And what are your memories of this diabetes centre?

Well, it was really lovely to have it, because it meant we could actually run diabetes education sessions; we could see people one-to-one - the nurses could; it enhanced the work that was done in the outpatient department, which were traditional diabetic clinics, where people would go in and have their consultation with the doctor, and it would be five minutes, ten minutes, out of the door. What the diabetes centre meant was, we could bring people, who were newly diagnosed with diabetes, in. Often they might be distressed, or even if they weren't, they certainly needed to learn a lot about managing their own condition. It meant we could do all that, and we had a place to do it, and a base for a small team to work. So, it was very, very important to set this up, to get diabetes on the map, and move diabetes care on, really.

And can you talk about the staffing of the diabetes centre?

Well, the staffing of the diabetes centre was, as I've said, we used volunteers. There were two nurses - my colleague and myself - based in it. The consultant and his secretary was based in it, and that was a good thing. And then... in fact, we had two consultants and two secretaries based in it, subsequently. And then we also, of course, involved other members of the diabetes team, like the podiatrist, dietitian and so on, and also, of course, relatives of people with diabetes; very important. The dietitians and podiatrists would come over, for instance, and see someone on their own, or they would participate to run group sessions. People could also see them, obviously, when they attended their outpatient appointments. But again, the outpatient situation, it was very much a bit of a cattle market, and whereas the diabetes centre, it gave people a bit of a chance to breathe. It meant we could all work together as a team. So, I

think it was... it wasn't an adjunct, it was essential; but it was a different way of doing things to just running a clinic.

What do you mean by "a bit of a cattle market" in the outpatients?

Well, it always felt like that, as a nurse. I mean, the diabetes nurses also worked in the outpatient clinic, so we saw the patients right the way through. And it was very difficult to listen to people who might be upset - the facilities weren't very good for that, and there were just streams of people, just coming in and going out, and looking rather confused. And, of course, they had to come in and have their urine tested, and they got weighed, and then they sat down, having registered themselves. And then they'd have to wait, and sometimes they waited so long, they went hypoglycaemic - and that was not unusual. And, in fact, it happened so much that we started... you know, we wrote... we actually developed leaflets saying, make sure you bring something to eat in case the cafeteria's closed; explaining to people that they, you know, they might be there some time. And I think that three hours, waiting for an appointment - a timed appointment, very often; they were waiting for a long time - it's just not good healthcare.

(15) When did these large outpatients' clinics for diabetes come to an end?

Well, they seemed to go on for a very long time. And we made some changes, I think, in Sheffield, by training nurses to do quite a lot of things that some doctors had done, which made the patients' wait better, less long. And I think people began to realise that this really wasn't a good idea, to have all these patients coming at the same time. And they started to peter out as the thinking changed, and people went to conferences, and the thing was being discussed. So, I would think, moving through the 1990s, they started to be looked at in a different way.

So, what were the key developments, then, while you were a diabetes co-ordinator, between 1988 and 1999?

I think the establishment of more diabetes physicians, under the leadership of John Ward; the establishment of diabetes nursing in the city; the training, not only of nurses, but also of general practitioners; and continuing the education of people trying to work together for diabetes. The diabetes specialty was thoroughly established in both hospitals in Sheffield, with dedicated teams in diabetes centres. And that was really crucial to the further development of other important... Yes, what I was going to say was the important area of eye screening, which, of course, is of particular relevance today. But, at that time, very few places had organised eye screening programmes. And I was fortunate enough to work with the health authority in getting the Sheffield eye screening programme established, with the ophthalmology team and the general practitioners. And it was a great project, and everybody was very proud of it, and rightly so. But what comes out of it all is about people working together as teams, and trying to be as little territorial as possible. I think, if you keep remembering what you're there for, which is actually for patients or people with

diabetes, and that's all it's about. Unfortunately, of course, human nature isn't like that. But I do think that, at that time, we were very lucky, and people generally were working together, with a certain amount of healthy rivalry, across the city.

(16) And what did you do after you ceased to be diabetes co-ordinator in Sheffield, in 1999?

Well, I felt very strongly that in working with the British Diabetic Association, which I'd been involved with on and off for many years, it was important that part of the BDA was a dialogue with general practitioners. And there had been discussions about this, that there should be a professional section of the British Diabetic Association dedicated to people working in primary care. And I felt very strongly about it. And working with many people in the country - GPs, the industry, the Diabetic Association, and others - we set up Primary Care Diabetes UK, which was a professional section of the British Diabetic Association. This already had a section for nurses, and a section for diabetologists. And so, my point, at the time, was, if you're looking after people with diabetes and working in a team, and you want to have a conversation, you have to have people there to have the conversation with. And, in general, it hadn't been recognised that primary care had such a place in diabetes care. And so, that's why I was seconded to the British Diabetic Association, as a consultant, to work, to set up a new section of the Association dedicated to primary care. And that's basically why I left my job in Sheffield. It was a secondment, so I still had the security of knowing I could come back, but, of course, when you leave a place, you don't go back, 'cause you have to go forward, on. And I'm glad to say that the team that I left are still here in Sheffield, and being very ably looked after by my successor. And having set up Primary Care Diabetes UK, I thought, well, that was a pretty challenging thing to do, maybe I'll stop at that. But then I realised that there was still more to do, and that was to, on a large scale, develop programmes of education in diabetes for general practitioners and their teams. And so, I couldn't do that in Sheffield, it wasn't possible, but it was possible at the University of Warwick. And that's where I went to develop these ideas, with a very able general practitioner, who's still there, Dr Roger Gadsby. And it was, again, the right place, the right time. And the University of Warwick, which has a reputation for entrepreneurship, took the idea on board, and we set up Warwick Diabetes Care. And I guess I finished my formal career there, in 2001, as a Director of Education for that organisation. And this was about training leaders to run programmes locally, in Scotland, and all round the UK, and abroad, and also to run programmes in and around the Warwick, Coventry, Birmingham area, so that general practitioners and their teams would, as it were, be empowered by a programme, which had a recog. . . was of a recognised standard. And so that's basically it, in a nutshell.

(17) And can you talk about your own diagnosis with diabetes?

Yes, I can. I was quite ill at the end of 1998, over Christmas. I remember having 'flu - real 'flu, not just a bad cold - and it seemed to take a long, long time to

get better. And I had been preparing to go to Cameroon to run a programme, for French-speaking professionals, in diabetes, ranging from doctors, nurses, managers, from forty countries - in French. And this was a programme we'd already run for English speaking Sub-Saharan African countries. And while we were there, we asked people, over this week's period, that they attended the programme in Yaoundé. We asked the participants to do their own blood sugars, and look after their diet, and so on, as far as they could, just to get a little inkling of what it might be like. The programme, itself, had been sponsored by a diagnostic company, who provided blood glucose meters for each person on the programme. And, in fact, none of them had blood glucose meters for their patients anyway, so it was... they were delighted to have these... this technology. And so, we all used these meters, and everyone did their blood glucose tests. And I was horrified to discover I had a blood glucose of fifteen millimoles, which is a little on the high side. And so, I shut it quickly, and hoped nobody had noticed. And then, unfortunately, someone did, and said "what was yours?", and I told him, and he said... well, he was absolutely horrified. And I said "well, there you are". So, we... In actual fact, that exercise, with forty people, produced one person with diabetes, and another person with impaired glucose tolerance - one of the general practitioners there. And I, actually, was completely... I just took this in my stride, at that moment, and said "right, I'll let you know, I've got a blood glucose of this. I want you to go away, and I want you to do a workshop. Put on your flipcharts, you've got a newly diagnosed middle-aged white woman. I want you to put down the management of this person", as part of their education. And so, off they went. They went off and wrote hundreds of things on the flipcharts, and they, you know, they had everything covered, came back, and fed back in French, and I sat back and listened. I should say that we had simultaneous translation.

- (18) I can understand some French, but not nearly enough to be able to deal with it. They fed back their results, and I have to say - then they asked for my comments - and I said "well, I think... I like what you've done, I like it very much. It's just like you see in a textbook. But", I said, "I've just been diagnosed with diabetes; I am absolutely shaken rigid. I don't actually know what I'm doing; I don't even know what I'm saying. But I guess that the person who's helped me most, this afternoon, having listened to what all you've said, is the young man over there who brought the blood glucose meters from the United States, because he came, put his arm round me, and said: how are you doing?". And actually, that's the only information I needed, at that point. So, what I found I could do was, my professional side was so tuned in to what I was doing, that my personal side almost disappeared completely. But actually, I was very, very upset, and cried buckets when I went to my room. I also found, I couldn't stop doing my blood sugar. And I kept doing it and doing it, saying "it's an American machine, it can't be any good, it's telling lies". And that was the sort of state of mind. And I would never - as a professional - would never have guessed that's how someone reacted. You know, in theory, people

are bereaved, they've lost their health; it's what it says in the books. But actually, when it comes to the personal thing, it's really important that... all the right medical things should be done, but the important thing... the whole progress of this person's diabetes is set from that moment in time, and if it's not well handled, then they will have difficulty. And that was the huge thing I learnt from learning I had diabetes. I could tell you an awful lot about what happened after that, but I'm not sure you want to know!

(19) And what was life like for you after you were diagnosed with diabetes?

Well, it wasn't as I had thought it would be. I sort of went off on a walking programme, and thought I had Type 2 diabetes, and was treated so, for quite a long time. And I discovered that there were certain drugs didn't suit me, and in fact I was really quite ill, with a lot of infections and fairly poor control for the first two years. And some of that was my not understanding that I didn't have conventional Type 2 diabetes, and I actually needed insulin, probably from the beginning, because I'd had pancreatitis as a child. And it wasn't until I went... someone else went back on my medical history, from childhood, that I remembered that I had been investigated for this, for unexplained abdominal pain. And, in fact, there'd been a paper at the Diabetes UK conference, I think, two years ago, or a year ago, which actually alerted me to remembering that I had had this abdominal pain, and kept being investigated for it. And it's been suggested that that was probably pancreatitis. And so, I had a slightly unusual form of diabetes, which neither I nor the general practitioner, nor anyone else, thought about, which is interesting, because what it teaches you is that you need to see people who know more about it than you do. And actually, it did prompt me to ask for a specialist referral, and it's only since this specialist referral that my... the understanding of my own diabetes has become much better. And that's interesting, because I've been a proponent of diabetes in primary care. But, in fact, when I went... did eventually crawl to the surgery, and ask for a prescription of insulin, the general practitioner didn't want to look after me any more. And now, of course, we're encouraging GPs to look after people on insulin. So, it's interesting how attitudes change, particularly when money's involved.

(20) What do you mean by that?

Well, diabetes care, now, has changed. It's changed dramatically, since the Quality Outcomes payments have come into general practice. GPs now get paid for providing certain items and ticking boxes, and that's the way diabetes care is now done. And, of course, if you want to have lots of ticks of people with good blood glucose control, you're perhaps more likely to want to put them onto insulin rather earlier than you did before. And so their blood glucose control would be better, because they're on insulin, and therefore you will get paid for doing such a thing. So, there are some interesting ethical questions about the way diabetes care was provided before, and the way it's provided now, and which way is the right, and which way is the wrong way.

And what's your own opinion?

Well, I think it's a sad way of dealing with healthcare. It's, as it were, goods for payment. The goods for payment happens to be, as it were, my blood pressure and my blood glucose. On the other hand, one could say that right across the country, this is a great improvement, because those things are being tested, and treatment of those patients is, therefore, having to be improved. So, there is, on the one hand, great admiration for this, that it's an improvement in diabetes care overall. But not, necessarily, on the quality of care for the individual concerned, who may feel just like they're being called up to have a box ticked. And that's my experience of it. I have actually been called up to the doctor's surgery, because one box was not ticked. They weren't interested in me; they were interested in the box. In other words, I hadn't, you know, had one item done, one blood test done, and that was that. So, you could say, in some ways, it's a very good thing. But what it's not doing is providing continuous care, quality of care, education, information, necessarily for people with diabetes, because really, all they have to do for the money is tick the box.

(21) And can you talk about the combination of being a health professional, and being someone with diabetes yourself?

Yes. That is a very interesting question, and it's... Having diabetes myself, having been working in it for so many years, has given me, what I suppose you could call, a dual insight into this condition. And I thought I knew something about diabetes. And then I found, when I was diagnosed with diabetes, I didn't know anything about diabetes, and I had to start all over again. And basically, there's a journey that you go on. You go on it as a professional, but it's a different journey that you go on as someone with diabetes. And even though you may know a lot, you know nothing. When you're newly diagnosed, you know nothing about your own diabetes. And that's the important thing. And the dual insight, I do feel, is really interesting, and, in fact, I gave a talk at the Isle of Wight conference after I was diagnosed. And it was about this insight of now having diabetes, and, you know, that I had... I felt changed. Not changed hugely - I hope I was reasonably empathetic before - but I have to say that most of the support I've had has come from other people with diabetes, because you're really on the level. And no one else, it doesn't matter how clever they are, can actually understand what it feels like to live with diabetes. And everybody has their own way of doing that. And it was because of that, that it was suggested to me - and with some other people who live with diabetes, and work in it - we've set up something called PROUD, which is Professionals United by Diabetes. And it's an organisation, which has been kindly, mainly, funded by Novo Nordisk. And we're setting up a network of professionals who live with diabetes - or they may be carers -but they work in diabetes. And it's growing: it's got about a hundred members. We're setting it up as a charity, and it's very soon going to have its own website. And we've been involved in commenting on research, we've been involved in getting together narratives of people united with diabetes - professionals united by diabetes - and we've now



collected, I think, twenty five narratives, which have been displayed as posters in various conferences. And they may be turned into a book, or we'll certainly be posting them on the website. And the narratives are, well, obviously stories, and they're very interesting. And they demonstrate how difficult it can be for someone who works in an area, like diabetes, who then gets the disease, or has a child with that disease. How do they get the support that they need? It seems to me that very often, people think if you're a professional, you're working in the health service, you know it all; you get on with it. And I do think that's been my experience, and it's been the experience of other people. And certainly, I'm sure we can share with you some of these narratives, which will be available on the website, at some point.

- (22) So, I've got two questions to ask, then, about how things have changed in the forty years or so that you've been involved with diabetes. And first of all, how have things changed in terms of training?

Well, I think, in terms of basic training, general training, in nursing and in other professions, clearly that much of that is improved, although I think the systems are so different, they're not really comparable between then and now. What I do know is that there are things that are very important, which - in diabetes - which have changed and improved over time, and particularly, say, in two areas. One is in the prevention of amputation, and the other is in the area of eye screening. And these are the two areas that people with diabetes fear most of all: they fear they may lose a foot, and they fear they may go blind. And they're very unpleasant complications, which people fear, and which we now know we can do a great deal to prevent, whereas forty years ago, that wasn't the case. In fact, I can remember, as a second year nurse training at St George's Hospital, I did a stint in theatre; we all had to do that. And I can remember being told, as a junior nurse, to stand at the bottom of the operating table with a wax bag. And without being told what was going to happen, a leg was amputated and just dropped into this bag, and I was told to take it away. And I did that, and went out to the corridor crying my eyes out, because I didn't know what to... I couldn't believe what I'd seen; was totally unprepared for it, at, what, sixteen or seventeen years old - seventeen years old. And I was told to... I wasn't told what to do with this. And I wandered along, and eventually I found a porter, who put his arm around me and said "what's the matter?" And I said "I don't know what to do with this", and showed him what was in the bag. And he said "oh, I know what we need to do with that", and he was very upset, of course, that I'd been put in that position. What is good to know is that hopefully less of those legs will be wandering the theatre corridors, in this country, because of good management of... good understanding of what goes wrong in diabetic neuropathy. And with regard to vascular disease, of course, there's a great deal can be done to save amputation now. And I do think that is a wonderful thing. From all those years ago, I've had an absolute thing about saving legs, having had that experience. And I do think that's a wonderful improvement in the care of people with diabetes, that we can really prevent many of the amputations. And then the eye screening, of course, which is wonderful that laser therapy is

available. People can have their eyes screened, and the diabetic retinopathy can be arrested using laser therapy, which... I mean, people just went blind. And that is... they're two very profound things about diabetes, which I appreciate from then and now.

- (23) Well, I was going to ask you two questions about how training has changed, and how the patients' experience has changed, and you've talked about two major improvements for patients. What about training, has that improved?

I haven't been in clinical practice for probably five years or so, but what I do... I do keep in touch with people, and people tell me things. Certainly locally, I do have evidence that the diabetes courses for nurses, and others - as we developed them for other people, as well - have gone; there are none. And there is very little... there's virtually no money for any training, other than for basic health and safety, and there is no money for continuing education, in the NHS, at the current time. I'm talking for nurses. I do know general practitioners do have some sort of funding that they can use. Nurses on wards... in fact, all staff, who aren't doctors - and I think it's almost applying to some of the doctors, as well - can't get time off, and there is no funding. And I don't see how you can run a competent workforce, people who are competent in what they're doing - as stated in the National Service Framework for Diabetes, which is what we're working to, since 2000 - I don't see how you can do that, unless you're committed to training. Turning to business, any successful business values its employees, and trains them well and provides them with continuing education. I'm not sure where the money's going in the NHS, but it certainly isn't going in that direction.