

94. Jenny Shaw

(1) Tell me about your background.

I was born in Oxford in 1962, and I attended a private school in Abingdon, until the point of my A Levels, and then I went off to college, in Oxford, to complete my A Levels. I come from a background that has not a heavy medical input at all, so the fact that I've always wanted to be a nurse is a bit of a mystery to me. I don't know where I got that idea from, but I always had this image of me floating down corridors and wards in this lovely hat and uniform. And that's what I wanted to do. So, I just got the absolute bare necessities of qualifications that I needed to do that. And this was in the days prior to getting a degree in nursing was common knowledge, which is a shame, because that's what I would have done, if I'd known. I think they were only just coming into fruition about then. So, my parents: my father is a press photographer, and my mother had multiple jobs - running pubs, being a sales rep for a printing company, running her own shop, her clothes shop - numerous jobs, so I couldn't actually label her as one particular profession. But they split when I was young, and I lived, for many years, with my grandmother, who was that sort of stable figure, and made sure I attended school and was sort of properly looked after, while my parents were up to other things. And then, at about the age of eighteen, I applied to get into nursing, and was accepted at Wexham Park Hospital in Slough, which is the East Berkshire School of Nursing, as it was.

And what are your memories of your training?

Training: I think it was a very pleasant training. It wasn't, I don't think, highly rigorous, probably compared to today's training. It was definitely in the orientation of a school, rather than a college. And I think you were fairly well-treated as school children, and I think that was probably the last days of that kind of attitude towards the students. And you were coddled the way through, really. However, you were placed on the wards: not as supernumerary, as they might be done today - you were definitely part of the numbers, and actually given responsibilities that were beyond your ken at the time, which was not safe practice. And you were left in charge of quite a few sick patients, and you weren't capable, just because you had a third-year stripe on your hat. So, I could see the change coming, and there were a lot of older tutors there who needed to move on to make way for new, fresh blood.

(2) And what are your memories of the course?

My memories of the actual course were it was very segmented into different specialities in healthcare. Specific to diabetes: it was a very small part, very tiny part, and it was portrayed as something very complex and difficult to understand. So, as a young student of eighteen, nineteen, you didn't want to know; "I don't understand that. I won't be dealing with that, thank you very much". And so, the patients, who were on the ward, probably got a very poor deal out of us. And I think that I can even safely say that about the staff nurses - the qualified staff - on the ward, as well.

What kinds of patients with diabetes did you encounter, during your training?

They were always very sick patients, who were in, or they were what was called 'brittle diabetic' - that terrible phrase - to come in for control issues. And the equipment we had to measure blood glucoses were absolutely antiquated. And I think the understanding behind these people's problems were totally naïve.

What was meant by brittle diabetes?

The word brittle diabetes was to someone who had difficult diabetes; it wasn't easy to control. Everything had been tried, and there was just no solution to it, and they were living lives of poor quality, because of their diabetes: hypoglycaemia, hyperglycaemia, ketoacidosis, couldn't hold down a job. They were usually young. So, this was termed brittle diabetes.

And were you encountering Type 1 and Type 2 diabetes?

No, I remember, really, mostly Type 1s coming into hospital with this problem. If it was Type 2, they were just coming in for surgery, or, you know, they were in a psychogeriatric unit, or something. It was an add-on, really, rather than their main cause of admission.

And how were the patients treated?

I think they were treated like automatons. I don't think, at that stage - we're talking late seventies, early eighties - as people who had issues, that they needed to be related to, to understand where these people have come from, what was really going on. It was very automated. It was: you do the blood sugars, you write them down, you record what food they've eaten, you give the insulin. A doctor would come in, and say something prescriptive about what the insulin dose was going to be, and that's all I can remember. Now, it may not be that that was what was going on, but that was my perception, at the time. I didn't feel there was much psychological care put into these patients.

- (3) Strangely, they always seemed to be tied to their beds. So, they weren't wandering about with normal activities that they would do through a day, they were sort of in pyjamas, in their beds.

And can you describe the blood testing?

The blood testing, back then, was a very old meter that you... well, it was only a meter when I worked in intensive care. On the wards, it was probably mostly urine testing - watching the colours changes - or I think there was just the evolution of the BM stick. And on the ward, you would use a whole strip, just to read off the colour, which could be interpreted quite differently from one person to the other, and so the variation of the reading could be large. Or, if patients were using them at home - some patients were starting to - you cut the strip in half to keep the costs down. These early strips - the BM strips - had sort of landmarks of colours, and there was actually, between one colour and another, could be quite a large gap of millimoles, which made it open to great error and interpretation problems, really.

And can you talk about your memories of insulin, at the time?

I probably was around at the time that they were swapping from the various strengths of insulin to the U100. And, being a student nurse, I wasn't terribly involved in that swap-over, which would have been done in an outpatient basis, and would have been a huge amount of time by staff to do that. Mine was learning, as a student, to draw up different amounts of insulin, according to the different strengths they'd been prescribed, and learning the maths to do that, and to not, you know, to be safe, and to not make errors. So, I was very relieved when I hit Geoffrey Harris ward, at the Radcliffe Infirmary, which was the diabetes unit, not to have to do that any more. It was all U100, with the same syringe.

Did you observe any errors being made, during your training?

No, I didn't, actually; no, I didn't notice any errors.

(4) And how much education was there?

Education for patients was barely existent. I was never taught very much about what to tell the patient: what should the patient know to be able to go home and live a relatively 'trouble-free life', as it were, in inverted commas. It was all done for the patient, and there was nobody out there who was a specialist who could enhance your knowledge at all. And the education that I got, in the classroom: I think we had one dietitian to turn up to talk about carbohydrates, and carbohydrate counting, I think, as it was called back then. And it wasn't very clear to us students; we were none the wiser when she left. And I think that was probably it. And I think we probably had another half an hour session on Type 1 diabetes, Type 2 diabetes, from a tutor, and that was it.

And then you were let out into the big wide world. What did you do next?

I stayed... my last placement was in theatres, general theatres, and I stayed on for a while there, as a staff nurse. And then I left that. And so, diabetes wasn't a big issue in theatres; not at all, really. And then in ITU, I met people who had diabetes in ITU, and I met my first meter that you put the BM Stick into, which I think was called a Reflux. And it was a big orange brick of a thing, and you had to put the strip in, twiddle the knob until the arrows met up on a dial, and then it would read off how many millimoles your blood test was.

For non-medics, can you spell out what ITU stands for?

Well, it's an Intensive Therapy Unit, or Intensive Care Unit.

(5) And what did you do after your time in ITU?

Well, as a total reaction to looking after very sick uncommunicative patients, I had a real yearning to actually deal with people and their issues. And I wanted to come back home to Oxford. Looked around at a few jobs - I was living near the Radcliffe Infirmary - and found that there was a staff nurse post in the diabetes and endocrinology unit, a ward called Geoffrey Harris ward. And I

knew I didn't know much about diabetes, but I thought it was about time I learnt. And I met a lovely nursing sister there, who... well, mentored me, and she taught me all I knew, very quickly. And I really loved it. I loved that link between nurse and patient; I liked the way nurses had a bigger role to play, and that it wasn't always medic-led; and that you could see it was a growing speciality. It was something that you could work on, improve the service, and you could see it had a future.

You were a staff nurse in diabetes and endocrinology, at the Radcliffe, from 1986 to 1988. Were there any changes in diabetes care, during that period?

I think this must have been a sort of pinnacle of change, over those years, because I think - unless it was just perceived that in Oxford - but the patient had... was the centre of the care, and that the medical staff were not. And that we were still having to admit all patients, either to start an insulin pen, or if they had control issues, or anything like that, they had to be admitted, because there were no diabetes specialist nurses that could facilitate that out in the community. So, that gave me the opportunity to learn a lot quite fast, with the support of Maggie Watkinson, who was the sister of the unit. And we realised that we could develop small education programmes, whilst they were in, that would help to keep them well and healthy outside the ward, and not to keep coming back into the unit. And then the ward started to have lots of phone calls from patients. So, not only were we trying to run a unit with other endocrine problems, and some neurology and diabetes, but because there was nowhere else for patients to go, they would be phoning in all the time to ask for help and advice. And we realised we were admitting people that didn't really need to be admitted, but there was nowhere else for them to go. And that's when the idea of getting one of the first diabetes specialist nurse's posts going came to fruition.

Before we move on to your becoming a Diabetes Specialist Nurse, can you say what the educational packages contained, on the ward?

It was really... it was nothing fancy. It was just a basic checklist of what we thought patients should know, like: legalities of driving, what to do when sick, how to dispose of needles and other sharps, do you belong to what was the BDA - the British Diabetic Association, do you know about hypoglycaemia. So, it was a long list, and it was a bit of a tick-box checklist, but it was a start.

(6) And now talk about becoming a DSN.

I became a DSN in 1988, after the hospital approached one of the pharmaceutical companies to sponsor that post for two years, and this was done from Eli Lilly. We had a really good relationship with pharmaceutical companies, who supported us both for our own education, and for patient education material, and just general information. So, this relationship worked both ways, for them and us, and they weren't just merely sales reps coming in any more, they were quite an integral part of the team.

What was in it for them?

Insulin sales was in it for them, obviously, at the end of the day. But you could... I mean, you went past that. These were people, and you did build up good relationships with them. But, at the back of your mind, you always knew it was about insulin sales and competition.

And what happened? How did you become a DSN?

I became a DSN... I was a senior staff nurse, at that point, and I applied, and nobody else did. And the senior nurse on the ward, Maggie Watkinson, had just got a post as a lecturer practitioner, attached to Brookes University, because nurse education was a really important issue, at this point, and it had gone to degree level, and they wanted representation from the area of diabetes. And so, she took that shortly after I'd got the DSN post. So, that was totally new to me, and I didn't really know what I was letting myself in for.

So, what were you letting yourself in for?

Well, I was young - I was only about twenty three, twenty four - and I, you know, full of enthusiasm, thought I could change the world. And I was given a little office in the corner of the ward - it was a cupboard, actually - so I was still in a ward environment. And I spent a week or two visiting other community nurses who had a DSN input, so they were other early-day DSNs; there weren't many. And I was really intimidated by the fact that everybody kept saying to me "but you're not community trained. You're not a district nurse. You can't do it", you know, "You haven't got the right background", which I never quite understood, but felt that they were older and wiser, and must have known better. But that view changed really quickly, to that wasn't the most important thing that you needed at all, and that you could come from many backgrounds and gain the knowledge to be part of a diabetes team. And what really occurred to me, and the light bulb came on in my head, that I was part of a large team of people, caring for an individual with diabetes. It wasn't just me and the patient; actually, there was a large team. So, there was the evolution into the team approach, which, through the eighties, was a huge model that people followed.

(7) And what did you do? Describe a typical week.

Well, in the early days, I don't think people really knew what I did. So, I was stretching myself by going out to the community, speaking to GPs, doing talks at lunchtime, in the practices, about insulin, or any basic things on diabetes. GPs were really keen to set up something called diabetes - or diabetic - mini-clinics, and so I'd help practice nurses set those up. I would see patients in my office, who normally would have come in to occupy a bed, to convert to an insulin pen; I would be doing that. Or people who had control problems with their glucoses, I could be doing that. And then, I became a victim of my own success, and the wards at the John Radcliffe got to know about me. So, I was always getting phone calls from the John Radcliffe, or other parts of the Trust, to go and sort out patients who had been admitted, and give advice. So, it got really busy, very quickly.

Can you describe these mini-clinics in the GPs' surgeries?

Well, I think the idea was that people with relatively early onset diabetes didn't need the specialist role to look after them, so not everybody should have to come into the hospital. And, perhaps, I think, naïvely I thought "well, if they're better cared for out there, they won't end up coming into hospital, because they won't be so sick, so let's care for them all in their own general practice". So, there was something called a little co-op card, where perhaps it would be better if there was shared care going on. So, they were seen in their own surgery, but perhaps six months later, they might be seen in the hospital, and then all the information about that patient and their last visit would be written on the co-op card, and then it would be passed over to the hospital doctor, who could see what happened on the last visit. But obviously, you know, these kind of shared documentations always fall at the first hurdle, as the patients lost it, or it wasn't filled in. So, they were in vogue for a couple of years, and then, I think, probably shelved.

You said you realised you were a member of a large team. Who were the members of the team, both in the community and in the hospital?

Well, the team was definitely the consultant, the junior doctors, the podiatrist, the dietitians, the practice nurses, the district nurses, I related to a lot for discharge of patients, and the GP.

Were there any dietitians or podiatrists going out into the GPs' surgeries?

Yes, because they would do community clinics, so yeah, I would relate to them as well, definitely. I also encouraged, during my visits to the GP, the idea of audit, within their practice, because it occurred to me that most GPs did not know how many people they had with diabetes in their surgeries. They didn't know how many people had Type 1 diabetes, or Type 2. And what they'd usually tell me is, they only knew by the repeat prescriptions being collected. So, that was a big issue. And some practice nurses were quite enthusiastic to find out who was out there, and once they'd found out the numbers, to document simple things like: had they had their blood pressure done in the last year, were they smokers, et cetera, et cetera. These basic things were commonly missed.

(8) You were a diabetes specialist nurse from 1988 to 1998. What other developments took place, during those years?

During those years, I still continued to try and promote the care of people with diabetes in the community. So, I started up something called the primary care diabetes course, which I wanted practice nurses to attend, to get a basic understanding of diabetes, and perhaps a little closer look at what kind of audits they could do in their own practice. That ran, probably, two or three times a year. And I would encourage GPs and other doctors to come and talk on it, as well. It also became totally evident that I couldn't cope on my own any more, as one individual. So, one, two... I think two other nurses came to join me, and one being the sister of the unit, Maggie Watkinson. She became a diabetes

specialist nurse, and kept her lecturer-practitioner role, as well. And we had another nurse join us as well, so that we grew in number. The work was still phenomenal, and we tried to divide Oxfordshire into sections, so we would take certain practices that were ours, and referrals from those practices. And the referrals within the hospital were also based on the fact of where did that patient come from, which practice did they come from. And then you would take them on; they were yours. And it became clear we couldn't do both. We couldn't be all things to all men, and try and do well out in community, and cope with the inpatient work from the hospital, and the outpatient work as well, and the staff training that we had to do. It got really difficult.

Was this because of an increase in the number of patients?

It was, yes; I think that was a big part of it. Over this time, the numbers of people with diabetes grew hugely.

So, how did you cope with this impossible workload?

I think we took on yet another nurse, which didn't solve the problem. So, we had to look at the way we were working, and it was to manage our time more effectively. So, we decided to cut back on the number of patient visits we would do at home. We couldn't cover all of general practice, like we were doing, as a facilitator role. So, it really just... we sort of incarcerated ourselves within the unit, and having all the referrals coming in from the hospital doctors, and those walking through outpatients, and sometimes attending the wards, if needed, and the GPs who shouted the most for help, really.

So, did the quality of care decline, during those ten years?

I can't... In one aspect, I think it improved, in the sense that you had nurses who had a specialism, and were keeping the diabetes profile high. And we were spending a lot of time teaching student nurses at Brookes University. We were trying to create link nurses on the wards, who could then cascade that education down to other nurses. So, in one way, I think it was quite profitable, but because of the increasing numbers of people with diabetes, that was counteracting our good work, really. And I did get exhausted; I got absolutely exhausted and burnt out. And happened to take maternity leave, at the time, and I think, probably, I went into the research post shortly after I came back from maternity leave, because I was just burnt out.

(9) Before we move on to your time as a research nurse, can you recall any other changes during your time as a DSN, 1988 to 1998.

Well, I think one of the biggest changes was the equipment for testing blood glucose monitoring. The technology improved, and the meters started to become easier to use. They weren't idiot proof, but they were definitely improving, and each generation of new meter brought a simpler piece of kit to use and less patient error. It was definitely, over this time, that the thought of patient empowerment started to emerge, and it was the patient's agenda that was becoming a priority, and the awareness of psychological support the patients needed. And that was

quite evident to me in a young adult clinic. We had a research project going, which had a psychologist attached, and how useful that was. And that was in the early eighties - probably '84, '85 - that we really needed that kind of support, and shortly after, the study ended and the psychologist went, and we felt very bereft by that. And we never ever got the money again for that kind of support.

What kind of support did a psychologist give to young adults?

They would either see them about behavioural problems concerning their diabetes, eating disorders, or relationship problems that were coming between them and their diabetes, which was really useful. Or they would give us advice about how we might manage a situation, rather than just blindly going on with this sort of patient-staff relationship that's probably quite wrong. You were heading off down the wrong route, and you just needed somebody, who knew what they were talking about, to put you on the right tack that you might take.

Can you give me some kind of example of where you might have been going wrong?

I can't remember anything in particular, but what I can remember is, you know, probably a teenager that was constantly coming back with hyperglycaemia or ketoacidosis, always ill, always saying "I've taken all my insulin, and I just don't know why this is happening to me". And you know there's something going on, and perhaps the psychologist would be able to talk to this person, and find out more about what was going in their lives, and probably give us help in order to understand what was going on too; as to why this was occurring.

And was there any sense that psychological help would have been a benefit to other older patients?

Oh, I think definitely. Definitely now, it would definitely be of help, because any chronic illness comes with a lot of stress, and affects people differently, and not just psychologically. It's probably just... you could label it counselling that's needed: depression, anger, inability to cope. And there's always lots of outside stresses in life that affect the way people manage their diabetes.

(10) And what other changes took place in those ten years as a DSN?

Well, I was also aware that when we went to any national meetings or conferences, that each year I went, there were just bigger and bigger numbers of staff, especially nurses. So, you know, that was a big clue, to me, that the nursing numbers in diabetes care was increasing quite fast.

What were the early conferences like?

They were very small, and because we were all quite new to that area, they were very exciting and everything was new. And you thought "yes, yes, everybody's really making a big effort here, and we can see it's a team effort". And that's what was always highlighted at these conferences, that how we're going to move forward, because it was a team approach between hospital and community, and all the staff involved. Also, looking at the psychological aspects of people with



diabetes was a hot topic, at the time. And you started to get to know people from around the country, and build that sort of infrastructure and that networking, which was really important.

And how do you think the care you were giving in Oxford compared with care around the country?

Well, strangely enough, because we were at a teaching hospital - a large teaching hospital - the emphasis was on medical teaching, and all that entails, and research. And it appeared to me that the general hospitals were looking much more at the delivery of their service, and how they were going to take it forward. So, I felt a bit left out of that. I didn't feel that was happening for us as fast, whereas, you know, quite sensibly, people assume, because we're in a teaching hospital, things would be moving really fast and forward thinking, and we would be at the head of it all. Well, we weren't, really. And it was also clear that the specialism for nurses and diabetes got even more specialised, you know: specialist midwives, specialist paediatric DSNs, in-service patients' nurses. So, yeah, even diabetes was dividing into specialisms.

And again, just staying with this period of '88 to '98, can you talk about changes in delivery of insulin?

Well, the biggest change, in the early eighties, was development of the insulin pen, which was a big boon. Before the pen, you were teaching patients to draw up clear and cloudy insulins with syringes, and mixing their insulins correctly, and not contaminating one bottle to the next, not getting air bubbles in. So, there were lots of patient error issues over that, and safety. And the pen, with their insulin cartridges and dial-up system, stopped all of that. And the whole concept of not having to use a syringe, but something that looked like a cartridge ink pen, was fantastic, that could be slipped into the top pocket or in a handbag. So, this really moved on diabetes care quite considerably, on the practical aspects.

Do you have any memories of the errors people made before the pens came in?

Well, mainly, as I said, it was the not drawing up correct amounts, not reading the little measurements on the side of the syringe correctly, or accidentally squirting one type of insulin into the other bottle of insulin, or drawing up but leaving huge bits of air in it, which weren't actually dangerous, but it took up unit space, so they didn't get the correct dose either. And people just felt very uncomfortable about using these syringes, which have sort of got that affiliation with drug use, and felt uncomfortable, socially, using them as well.

(11) Now talk about becoming a research nurse.

I got the job as a diabetes research nurse in 1998. I'd come back from maternity leave, and worked a short spell, half-time, as a DSN, and got really exhausted by it. I was getting that burnt out feeling - with a young family at home as well - with large, large numbers of patients, and the community responsibility as well. So, I realised that there was a diabetes research job going - and I still loved diabetes, and I didn't want to leave it - so this was a great opportunity

just to sidestep slightly, and experience what research would be like. And it was great. It was quite a high learning curve, because research - the process of research - is something that was completely new to me. Whilst I had the clinical knowledge, which was a good thing to have as well, I did need to get a little bit more education about research, which I did. And I embarked on running some... a couple of long-term studies, one of them being the CARDS study, which was five years long. And patients had already been recruited on to that, so I took on the responsibility of collecting all the data off them for their visits, monitoring their therapy, because this study was looking at lipid-lowering statin, and the benefits of that for everybody who had Type 2 diabetes. So, that was the main principle of that study. But I had to look after their diabetic aspects also, because they were with us for a long time. They didn't attend ordinary outpatients as well as coming to the study; we would do everything. We'd treat them holistically, and do everything for them whilst they were with us. Of course, they were happy to stay for the whole duration of the study, and we didn't have anybody leave.

You say that they'd already been recruited. Can you talk about your first experiences of trying to recruit patients for a study?

Oh, recruitment is the hardest part of any study; it's absolutely the hardest. If you can recruit, the rest of the study is relatively easy. But convincing patients that research is a good thing to do, and it's something that would be a positive thing for them to do, is tough. And you always have a set of inclusion and exclusion criteria, about the type of patient you can recruit in to the study, and sometimes they're quite prohibitive and very difficult to follow, in order to get your patients in. So, you have to be a bit of a sales person, and try and sell a study to patients, and that it would be... it could be quite a good thing for them to do.

What are the advantages for the patient?

Well, the advantages for a patient, in a study, is that we'll see you over a long period of time. You'll see the same staff, you won't have to reiterate yourself, we will get to know you, you will get to know us, whereas, in most outpatients, you probably see a different doctor every time. We'll have time for you, to give you that education that you may have missed out on previously, and that we can do it over many months, many years. And hopefully you'll come out the end, knowing a lot more about your diabetes than you did before, or feeling more confident.

(12) You've now been a diabetes research nurse for ten years, since 1998. What have been the big changes, during that period?

I think, probably, the changes in medication has been a big advance. We probably had the, about eight years ago, I should think - yes, eight years ago - the bringing in of analogue insulins, which has made a big difference to the way people manage their diabetes. We had inhaled insulin, which seemed like a magic bullet, but that came and went, unfortunately. I had only one patient

start on that, but it's been withdrawn, now, because it's not been recommended by NICE, and it's very expensive to use. And it's quite a lot of kerfuffle to inhale these by the equipment, so, unfortunately, that's left us. Insulin pumps have progressed dramatically since I used to start people on them, in the eighties. They've become very small, very sophisticated piece of equipment. But they're not as widely used, probably, in the UK, because of the expense of them, and the expense of the consumables, or the needles that are required to insert them. The costs can rise quite heavily, over a year. For Type 2 diabetes, not only have they benefitted from the analogue insulins as well, but something called GLP-1 or Exenatide has been released, which is another new and novel way of controlling blood glucose in people with Type 2, and it's injectable but it's not insulin. And there's something called DPP-4 inhibitor, which is another method of controlling blood glucose, which is not insulin or tablets, sulfonylurea tablets. Group education has become increasingly important, rather than all the just... the scattergun education that we used to do with people on an individual basis, as and when we could. The type of group education would be: people starting on insulin - special groups for; people... or women who want to get pregnant, so pre-pregnancy groups; weight management groups, mainly for Type 2s, probably, if you've got a weight issue; something for dose adjustment for eating and insulin adjustment, something called... a course called DAFNE, and there's another course we run here in Oxford called InSight. These are all really important parts of the service, now.

(13) And can you talk about changes in the Health Service?

Well, over the last ten years, the Health Service has had to take note of something called the National Service Framework - the NSF - and these set standards that trusts should be meeting for the care of people with diabetes. There was a ten year deadline to have reached a certain standard on different aspects, and whether everybody has, I'm not sure, but the group education was definitely part of those standards; personalised education to the individual. So, I think many trusts are making headway with that; as far as the rest, I'm not sure. And there's been a big emphasis of taking all the people with diabetes who are seen in hospital, and those who aren't endowed with complications are seen back in general practice. Primary care trusts want to... well, there'll be some financial implication for putting all the care back into general practice, and only referring the more complicated patients. But I think there's some resources issues about why that hasn't happened for us, yet, here in Oxford, anyway.

You mean care hasn't moved out of the hospital?

No, they tried to, but I think the GPs were unable to cope, at that point, and so that that process had to be halted temporarily. And eventually the care will be focussed more out in primary care again.

Well, as you were involved in setting up those mini-clinics, and getting care into GPs' surgeries, what are your thoughts about the kind of care that patients get in hospitals, compared with GPs' surgeries?

Well, I think, in an ideal world, it would be great to have people back in general practice, but I think, by definition, GPs have a lot on their plate; you know, they're generalists and they have to look after everything. And looking after people with diabetes can be quite a complex business, and it needs a lot of infrastructure with it for the communications to be reliable; that, you know, if you've done their eyes that the right people know; if they need treatment that all the blood tests go to the right place; that they're followed up correctly, you know. Communications out to the podiatrists and the diabetes specialist nurses need... there needs to be a smooth communication. And GPs and practice nurses need quite a lot of education as well. So, it's a lot to ask of somebody who's working in a general practice.

- (14) Looking back, now, to the early eighties, would you like to contrast what it was like, then, for somebody with diabetes, and what it's like now?

Looking back at the early eighties, I think things were a lot tougher, really. For somebody who was converting from tablets to insulin, there weren't any group education sessions you could join. You may have seen the GP, and hopefully you may have seen somebody on a ward in a hospital; you may have even needed admission onto the ward, if there wasn't a diabetes specialist around. It would have taken a lot longer to learn how to do blood testing, because you may not have had access to your blood testing strips. And you would have to cut them in half, because they weren't on prescription, and then learnt how to wipe them properly, read the colour off accurately, which was very subjective to who could tell what colour it was on the tin. You'd have had to learn to draw up with a syringe, and all the problems you could ensue doing that. And probably, once you'd got used to injecting yourself, you may not have had much more education beyond that, if it was a busy ward that you were on, and been discharged home. And you may have felt that there was nobody out there that you could talk to or get help from. Now, hopefully, today, you could have been started on your insulin, maybe, by your general practitioner and practice nurse, who have got good skills in that area. Not all GPs and practice nurses do, but that may have happened. You may have been assigned to a patient group, where you could have got some more education over a few sessions. You'd have definitely been given a meter to use, which would have been very simple, and wouldn't have given you much trouble, and there wouldn't have been room for much error. And probably you'd be given an insulin pen, so you wouldn't have had any of the problems of drawing up with a syringe, and your nice pen: easy dial-up, easy to give, very sharp, fine little needles, and slipped into your top pocket or your handbag.

- (15) And then, you used the phrase, at one stage, that you love diabetes, which is perhaps not a phrase that any patient would use. What did you mean by that?

No, probably patients would not say that. When I say I love diabetes: as a nurse, I think it's a fascinating subject. And it's a lot to learn, and, you know, it's taken me twenty years to get to where I am now, and I still have more to

learn. And what I value is that diabetes may be all the same in all the textbooks, but it's not all the same for each patient. It is completely different, and it's a challenge how to meet that with each patient, and adapt it to that individual, and listen to what they're saying. And we do have a great armoury of insulin and equipment, now, that we should be able to do that with relative ease. And it's still progressing, it's still developing, and in ten years from now, who knows where we'll be. Because the number of people with diabetes has considerably increased, over these decades, there's a lot more people out there who are elderly, who need to remain independent with their medication, and how they're giving their insulin, and how they're doing their blood glucose recording. So, even the equipment's become refined to individual needs. So, somebody who's elderly with poor dexterity, there are bigger, fatter pens, which are really simple to use, with big dials that are great for them. But there's still the small refined pens for the business man, who just wants to slip it discretely in his top pocket. There's big display meters that are still neat, but have big display for poorly sighted people or elderly people, who can't see small read-outs. Meanwhile, there are tiny little meters that record everything you do, what exercise you do, how much carbohydrate you eat, it might even tell you what insulin dose to give, and it's got a tiny read-out, and it's much smaller than a mobile phone. So, all the technology, whilst it's developed, has got more specialist for different people's needs.