

Susan, Baroness Masham of Ilton interviewed at home, 30 August, 2012

Jon Newman interviewer

Could you start by talking about the accident that resulted in your spinal injury and the treatment that you had for that

Well it was my fiancé's 21st birthday and we celebrated it at a nightclub in London and, because I was riding in a point-to-point the next day in Wiltshire, I left at midnight because I wanted to be fit for the race and my fiancé came with me. I was riding in a point-to-point which is a race over about 24 jumps and it was at a place called Cricklade which is quite near Swindon and the horse I was riding, I'd ridden the week before and we'd been third, and I was full of hopes that we might win, and we were going well when suddenly over one of the jumps they put an extra jump in and it had had a warble fly and I've always thought at that moment the warble fly may have pressed on its back. (and warbles get into the spine of cattle and horses and they're an absolute curse) Anyway, the horse put this extra jump in and the next thing that happened was it fell and I went down with it and it rolled over on top of me, and one of the horses coming behind kicked me in the stomach. I was then picked up by St. John ambulance - and they would have had to pick me up fairly quickly to get me off the course before the horses came around again - and I was taken off to Swindon Accident Hospital. I did have an enormous haemorrhage and I vomited blood and it poured out from down below and I lost pints and pints of blood. I was rhesus negative and they ran out of blood locally and had to go to Oxford to get more, that saved my life. Also they knew what to do because three weeks before a young Indian girl had been sleep-walking and walked out of a window and fallen and broken her back. So many general hospitals don't really understand and know about spinal injury but because of this girl and the complications she'd had they were able to save my life. Because the haemorrhage was really one of the important things, I've seen a lot of blood but I've never seen as much as I lost. That was really quite interesting because later on in the years afterwards my blood group changed from negative to positive which is very unusual, but I'm told it was because I had so many blood transfusions and the antibodies had changed.

Well, 24 hours later I was transferred to Stoke Mandeville hospital and that is a very important part, I think, of the treatment of spinal injury. Many spinal injuries have other complications and those have got to be stabilised and then it is terribly important to go to a spinal unit where people understand and there is the right equipment. I mean how many general hospitals just don't have the right equipment and the staff who know what to do and how to move you, how to stop pressure sores, how to treat the paralysed bowels and bladders? Anyway, I arrived and my brother by that time had come down to be with me also as my fiancé was and I remember on the journey from Swindon to Stoke Mandeville he stuffed a bit of chocolate into my mouth and that was one of the most dangerous things I could remember. I had just about enough strength to spit it out but it is an important factor when you're dealing with someone who is crucially ill you don't give them anything to eat such as chocolate and he was only being kind because it's very emotional when someone has an acute spinal injury for the nearest and dearest, they get very emotionally upset.

What were your first impressions of Stoke Mandeville?

Well when I arrived at Stoke Mandeville the first doctor I saw was Dr Jack Walsh, and by that time 24 hours after my injury I was in agony because I not only had a fractured my spine in three places but I'd actually fractured a whole lot of ribs as well. Ribs are agonising, and it was extremely painful and I do appreciate pain, I do appreciate people now who have a lot of pain. But the best thing that happened to me was Jack Walsh saying to me "don't worry too much, the pain will start going in about three weeks' time" and that was the sort of light at the end of the tunnel, because at the beginning you were in great pain. Then my next memory (and it was a long time ago, this was 1958) was Ludwig Guttmann, the doctor in charge, the one who had founded the spinal injury unit, he came in to see me. And I remember him saying "Well at least you've got feeling in your breasts". That was the first memory I have of him, and also he said "You must drink, you must drink". When you're in spinal shock you lose your taste and your smell, and because you have no taste you really don't have the urge to eat or drink anything. But he said "it's very important to drink" and I remember him as a very positive person, forthright.

We were encouraged to do things as soon as possible. The first few weeks with so many fractures were pretty painful. Guttmann did not agree with pain killers and in a way I think it's a good thing because I think people can get addicted to them. I now work in the health service and work with all sorts of addiction and one of the problems is prescribed drugs and I remember that very well.

We got turned every three hours. If there was an extremely thin person they got turned every two hours and in those days we were placed on large Sorbo-packs with a space in-between so the air could circulate and every three hours we were picked up by orderlies, many of them were from foreign countries they didn't speak much English, and they used to pick one up and I remember one particularly big strong one from one of the East European countries and he used to pick one up and squeeze one and my ribs! I used to yelp and they used to call me 'Wait' because I used to brace myself and say "Wait" because I knew he was going to squeeze me. But the positioning of the pillows was terrible important. If you are uncomfortable and you can't move then pillows are very important. But they would turn you from side to back to side and back again, and the treatment of skin was very important to stop pressure sores and that's why one's got to keep as fit as possible to stop pressure sores. Anyway, we were encouraged to do things. We had physiotherapy from the start and I had a charming physiotherapist who was Australian and perhaps she became one of the most important people in my life. Not only was it the doctors at Stoke Mandeville, it was the physiotherapists and the nursing staff and the orderlies, you know they worked very much as a team. And the occupational therapists. Well on one occasion we were all supposed to make baskets and on the ward round, the ward round always consisted of Guttmann and the ward doctor who was called Dr McAlus(?) and his next Dr Walsh and the junior doctor who came at the same time as me, Dr Hans Frankle, and he was the sort of junior doctor on the ward, he's now a professor and is actually retired. Then there were some junior doctors and there were post-graduate nurses, there was a sister, there were various nurses and there were the therapists. Anyway, my basket was handed to Dr Guttmann and it fell to pieces in his hand and everybody laughed. He was not amused, and he accused me of not concentrating on basket making.

But then once we got up and after being in bed for really quite a long time, several months, probably about 9 weeks, I got up slowly. First time I got into a wheelchair I passed clean out because of the circulation. Slowly one became acclimatised to the wheelchair. For a paraplegic with the full use of arms and hands, not being able to feel one's behind, you felt rather as if you felt you were sitting on a cloud. For tetraplegics it's even more so, so balancing became a very important part of

physiotherapy, and they taught you to balance again. They did passive movements with the legs and my physiotherapist, one confided a lot of in her, and I said the one thing I wanted to do was ride a horse again. She didn't say you can't, and later with a saddler from Newmarket we invented a saddle with a built up bank back and later my brother-in-law gave me a Highland pony for a wedding present, who was good and substantial and could carry the saddle. Then my young offender boys (in those days they were called Borstal boys) they dug a pit and the pony walked down into the pit and that was on the same level as my wheelchair and I got on there. But you know it was a way of having contact with a horse again. But you know all these thoughts came up and the physiotherapist was the most important person because she had time to listen, and being Australian she was used to lots of the sporty things. It was not long before Guttman, his inspiration of sport for rehabilitation and me being quite a keen sporty person because I used to play in matches at school and various things, you know I was introduced to sport. It became very much part of our rehabilitation as patients. We are now years later concerned with the modern spinal units in that they are not using sport as part of the rehabilitation as they should in many cases.

Just to deviate a bit, I founded the Spinal Injuries Association a few years after I left hospital because there was not an organisation who spoke for people with spinal injuries, so about 38 years ago now we founded the Spinal Injuries Association with some colleagues because all sorts of people were having problems. But I had good support from lots of friends, and friends are very important people. Some of my horsey people used to come and help feed me because when I was lying in bed it was extremely difficult to eat, especially with the rib situation and if you're lying in one position. My brother used to come down and read to me and I used to promptly go to sleep. That often happens to people and it was a calming and good thing, I know lots of people who have similar situations and then they feel guilty because their relatives have come to visit them. Of course my fiancé was there and he used to visit with my dachshund who he looked after, I had a dachshund called Hans who was named after one of my skiing instructors, and on one occasion I gave Hans my supper which was a fried spam fritter and he was promptly sick in the middle of the ward. Stoke Mandeville has never had good food, they still don't have good food. Hospital food is one of my big issues, that it helps people to get better quicker, and I'm delighted now that there's going to be, we hope, a Bill in Parliament on better hospital food. But for long term patients it's very important. Some patients I noticed who'd come from other hospitals were like Belsen people, they were so thin and they were so malnourished so food is very important, as it still is. Nowadays many people in hospital live on supplements and Stoke Mandeville has just never put good emphasis on food. There was a French doctor who was part of the staff, Dr Paul Dolfus and he had had polio so he zoomed around in a wheelchair and became a great friend. In fact my husband was godfather to one of his children who is now an eye specialist. It was good to see people in wheelchairs doing useful things and our philosophy at the Spinal Injuries Association is life doesn't stop when you're paralysed.

How soon were you made aware of what the likely outcome of your injury would be for you? How soon did you understand that?

Well Guttman and the other doctors used to come around and prick pins into one to see how much movement one had and physiotherapists used to try and get ones feet moving and things and then one had procedures where they'd take fluid off your spine and then you measure it. We had a wonderful nun working in our ward and one of her fellow sisters had broken her back in Dublin and had come over and she was in the next door ward, and Sister Mary-Pierre became a great friend of mine but she was a marvellous nurse and one soon realised how important good nursing was. There

used to be post-graduate nurses who came down to train from the London hospitals on spinal injury, and that was an important factor. That doesn't happen quite like it used to happen and it's very important because there are certain problems, such as your bladder and your bowels, and bowels never work very well in hospital. It wasn't until I left hospital that I got mine working properly. One has to do a manual evacuation. All that gets taught to you but actually when I left hospital because I was eating a different sort of food I didn't have to take lots of laxative, which aren't very good for you really, it's better if you can make the bowel work naturally. All that one had to take in and I remember one particular night sister who used to say "don't forget to feel your buttocks every night, if there's a bump and it's hot you know there's a problem – pressure sore arriving", and it's something I've always remembered because you can feel yourself even if you can't feel internally, and one's got to learn to look after oneself because there's no doubt about it; living in a wheelchair is quite hazardous and of course it's a challenge. One became great friends with some of one's fellow patients and I'm still very friendly with one and she was an inspiring girl. She'd come off a motorbike and broke her back, same level as mine, but also one of her arms was paralyzed so she only had one arm, so she got a special wheelchair with a special wheel to balance it out so she could push her wheelchair. One saw all sorts of different people, I had a huge Swiss friend who had fractured his spine driving his car, I think he was a racing driver, anyway he was very interested in hand controls and cars and recommended Fenian-Johnson hand controls which I have had to this day on my cars and they're a ???? (24:48) because there are so many different types of hand controls the only problem is that my Fenian-Johnson type now are more expensive than any other type of hand controls. But I've driven so long I don't want to change, that's very important. You know Stoke Mandeville did become part of one's life.

Then one started doing archery, that was one of the first sports, very good for one's balance and also good for concentration and I met a fellow jockey who had really tremendously depression and felt that the end of life had come, and then he started doing archery and he got the idea that if he could do archery of doing accountancy and trained as an accountant and then married one of the nurses and became an efficient accountant. So sport does bring people onto other things and I was introduced to table tennis which was my number one sport and I took part in the international games later on. I went to Rome in 1960 and this was the first international sports abroad so we had a great time. Rome was interesting. There were about 400 competitors from about 24 countries and we arrived in the Rome to find that the Olympic village where we were housed was built on stilts, and how were they going to get 400 wheelchairs up and down? They had to bring the Italian army in. Anyway, there was a huge Olympic swimming pool, very exciting. I won three medals for swimming with Margaret Maughan I won one of the first which was for breaststroke swimming and one night we were invited by a friend to go and have dinner by the Trevi fountain. I lost my medal, my gold medal. What happened I think was I put it in the side of my wheelchair and I think it just dropped out. Anyway it hit the Italian press because they thought I'd thrown my medal into the Trevi fountain. Rome we felt was wonderful because we got very friendly with members of the different teams and it wasn't too big you know, 400 competitors. Now the sports have become huge and there are thousands. But you know the pioneering stage was a wonderful stage, and I was fortunate enough to go to Tokyo and we were housed in pavilions and my husband came with us to Tokyo, he didn't come to Rome, and the Japanese just would not believe that we were married. I mean disabled people didn't get married in their idea. So the Paralympic games coming to Tokyo taught the Japanese a lot.

Where was your husband required to be in Tokyo?

Oh we won, we won it out and he was allowed to stay in the pavilion. He and I shared a room and he actually became extremely useful because the other girls in the pavilion always liked a cup of tea in the morning and he used to go and bring them a cup of tea before they got up. I'm not a tea drinker so I wasn't one of them, but he used to look after the others and he was extremely good. To him spinal cord people were just people, but not to everybody and not particularly to the Japanese. We really felt that we had been useful there teaching them, and now they come over with a big team, so it's good. But to some of the countries where we went it was a new thing. We also went with the equivalent of the Paralympics to Israel, to Tel Aviv, and because they were in Atlanta in America and America of all countries couldn't accommodate the wheelchairs, so Israel stepped in and we had a very interesting time there. I was extremely fortunate because I had a friend, another nun, who was very much working and well known to the United Nations and they used to lend me a car with a chauffeur and the driver would drive into the desert and we had a wonderful time. I just loved the desert. One day with one or two of the other paraplegics we went down to Jordan and there was shooting all around us because there were problems there! I've never known the driver to turn the minibus more quickly and we shot off up the road. In our travels we did have some experiences.

I also went to the Commonwealth Games and on our way to Australia, we went to Perth Australia, we stayed in Sri Lanka en route and we were unloading all these wheelchairs from the hold, getting the right person the right wheelchair not an easy job, and the monsoon rain came so we experienced the monsoon getting into our wheelchairs. We had all sorts of adventures. I think it was in Japan before we left, I'm always a bit wary of flying and I noticed there was some oil on the ground which I wasn't too happy about because I thought "oil leak" and a few hours into our flight we had to turn back because there was an oil leak, so I had let it be known that there was an oil leak. But it was a huge feat, even in the early days, getting people in and out of the aeroplane. We had wonderful helpers, the volunteers really are important people. In the early pioneering days some of the coaches would come with us and some of them, two of them particularly I remember, were trained physical gymnasts who had been in the RAF. The RAF seemed to do a lot of this sort of physical sport and they were really dedicated people. Nowadays everything has changed. We used to raise a lot of money through various means, we used to run a horse show up here in Yorkshire for supporting the paraplegic games. Now they are so huge and they've got sponsorship, and I think without sponsorship they wouldn't be what they are today, because everything's got big, important, special wheelchairs. And some of the basketball players go through many a wheelchair, you know they're quite strong games they fall out of their wheelchairs, they crash into them. And the rugby which is new to me I think is even more than the basketball. Some of the developing countries don't have sponsorship and they don't have the sort of wheelchairs that our competitors have, so I think it's good because one's teaching other countries what can be done.

Going back to the games that you attended, what were the different sort of satisfactions you got from on the one hand swimming and on the other hand table tennis? Did they do different things for you?

Well, certainly you have to be competitive, you have to practice a lot, to get up to a standard you have to practice a lot and be dedicated. When I was seriously doing table tennis I used to practice up here in Yorkshire with the Northallerton table tennis league, all able bodied people, and also I had a great friend called Neil McDonald who was a very keen player, he used to come and stay and in hall I used to have a table tennis table and he had a wonderful machine which spat balls out and we used to play for hours, you know hours. I'm going down this year to watch the table tennis, I think to the

semi-finals, but it's an extremely good game. I played so much and I did play all over the world looking at it, because we went to all sorts of interesting places, but I more or less wore my shoulders out and that's why one has to be... there is a saying "all things in moderation" and with big things like putting the shot one really has to be careful because as one is an older paraplegic now, one has to preserve the use of one's shoulders. Paraplegics use their shoulders for transfers, for getting on the lavatory, for getting into the car, for getting into bed, dressing. Your shoulders become your legs as well as your arms, and you put extra stress on them. I went to Greece for a holiday a few years ago, it rained a lot and there was table tennis there, one of the people I was with was a good table tennis player and I was still pleased that I could beat him. But I do have to preserve my shoulders. When I look at these youngsters racing down the tracks it's a great thing, but when the years roll on one's got to be careful. And now so many of my aging paraplegics are having problems with their shoulders. You see we need good doctors who understand the very many different problems; they think "well they're in a wheelchair, they look fit" but actually shoulders are a very important thing. One has to be careful. Sport is a tremendously good thing; it inspires and gives one great pleasure especially if one has a competitive spirit, but actually I don't put every single emphasis on the winning of golds. For some people I think simply taking part is a very important aspect because they're actually taking part in a challenge. Some people just aren't as good at sports as others, they can't all be brilliant. Some people will hold back and say "well I can't do it, they're too good for me" and that's why we wanted it encouraged at the hospital level so that they can go out into the world with sport and then join clubs and things. I've just learnt that some of are picked up after they leave hospital by various clubs, and I feel that is part of rehabilitation, part of getting better, part of taking part, part of mixing and meeting people. That was Guttmann's philosophy and in the early days he had a lot of opposition: people used to say "they'll only live a few years" but he was certain that if they were able to take part in sport they would be able to take part in everyday work and be taxpayers. That was his great thing, to be a taxpayer, which of course many of them do. A lot of our members are all sorts of people. We've had young doctors, we've had legal people solicitors, farmers. One farmer I knew had broken his back with one of those huge bales which rolled on top of him and later he still ran his farm. Life has to go on, life mustn't stop.

Just going back to your competitive sporting days, were there significant moments there that stick in the mind?

There was one significant moment in Tokyo when I was playing double tennis with my partner Gwen Bugg and I stretched for a ball and my chair tipped over sideways and I landed on the floor. I think we were playing the Italians at the time and it was the Italians who picked me up and put me back in my chair. We continued the game and we won gold and I thought that was a really sporting move, if they'd left me sitting there the others would have won! I remember also doing backstroke swimming and there was a bar across and suddenly I found myself on top of the bar on my back not being able to get off. Luckily a Norwegian coach saw me and jumped into the water and pulled me off. You've got to be careful, things happen very unexpectedly.

You know there's always people much worse than yourself when you're in a spinal unit. Speaking of Norway, there was a Norwegian at the games who had no use of his arms and he played table tennis in the high cervical category. They would place the ball on his bat which he held in his mouth and he played the most amazing game. Huge shots with spin all sorts of things; so even the very disabled could take part in sport. He impressed me hugely. There were all sorts of different characters but it's the international spirit which I found really interesting and one made some good friends. Different

countries are good at different sports, and the Americans and Israelis always used to be in the finals of the basketball. Actually in recent years the Israelis seemed to have lost that huge competitive side of it. The Italians and the French were always good at fencing. My biggest competition in table tennis was an Austrian woman of the same lesion as me. Sadly she's now died from cancer. People with spinal injuries can get all sorts of problems that other people get, and that's why you want to look at the whole person when you're treating them. This is one of the dangers; various things like cancer can be forgotten. One had to compete in the national games to take part in the international games, one had to qualify.

And they were always at Stoke Mandeville?

In the old days the national games were always at Stoke Mandeville. I think it could be different now, I'm not quite sure. But the classification is tremendously important because there are complete lesions and there are incomplete lesions, and of course the incomplete lesions have much more balance than the complete lesions and even somebody who is highly paralyzed from the neck but is incomplete can be better off, as far as sports are concerned, than somebody who is paralyzed just from the chest down but is complete. So the classification is very important. Nowadays when lots more people with different disabilities are taking part the classification must be even larger. In the early days when we were campaigning and we were really pioneers of sport, there weren't the problems of drug taking or that sort of thing. That has developed with modern society, and also the hugely competitive, I think it's more competitive now and more pressurised than it used to. One always had pressure on but I think nowadays it's even more pressurised. Instead of doing two or three sports like we used to do, today people concentrate more on one sport.

Do you think overall that is good or bad or just different?

I think it's different, but doesn't want to keep other people out because of being so good that they feel they'll never achieve that. One's got to embrace as many people as possible because it's good for them. I saw the under-22 basketball team the other day. There was an amazing service at St. Paul's cathedral which was splendid, and it brought in a lot in a short time, one of the things was the basketball team in the middle of the service at St. Paul's and these young people were so good and really amazing. So it's important that people can see what they're doing, and in the old days there wasn't half as much publicity as there was now. Take 2012, there's been a huge amount of press and I've been happy to speak to some of the local people, BBC York and Leeds, and it's good that there's interest right across the board. But in the old days didn't used to be as much as there is now.

What was the media coverage when you went to Rome in 1960?

There was a lot of coverage in Rome, and they photographed a lot. There wasn't that much back home. I had a great friend called Pauline Folds, she used to swim and did archery, she was local to me up here in Yorkshire and we were given an honour at the city of Ripon. The Ripon Rowels, the Ripon Spares, and that was very nice, they recognised us.

That was in 1960 after the games?

No I think it was after Tokyo. We used to practice in the baths at Ripon. You see facilities for people practicing have now got better. A lot of the swimming pools now have lifts but in the old days they didn't. That has improved.

You had to have someone to hoist you out?

Yes, yes. But nowadays quite a lot of swimming pools have hoists and that's good. Not all but that made a huge difference. Something that Guttman was quite pleased about was when I came up to Yorkshire I saw that I was extremely fortunate because my husband's grandmother gave my husband and me this house which we designed which is good for a wheelchair. It made all the difference to our lives. But I discovered there weren't that many housing projects good for people using wheelchairs and all sorts of things. I started doing voluntary work around, gave a lot of talks about the sports and Guttman and the philosophy of sport and rehabilitation. I then got invited to be a member in the House of Lords in 1970 and Guttman was very pleased about that. He said to me "Oh you must make them aware of other disabled people." There was a friend of mine who also had a spinal injury, Davina Darcy de Knayth who also took part in some of the sports and she was a hereditary peer. There was Martin Ingleby, another hereditary peer, who'd had polio in the army. There was another point-to-point injury like myself called Mike Crawshaw who was also in the House of Lords. They hadn't made their maiden speech, so we all made our maiden speech on the 1970 Chronic, Sick and Disabled Persons Act which was an Act of Parliament by Alf Morris, who had been the first minister of disabled people, who sadly died this year. Alf won the ballot in the House of Commons and Lord Longford who was father of the House of Lords, he took the bill there and we all made our maiden speech. So that was good, and you know we brought all sorts of things in to make life easier for disabled people such as housing, such as telephones for disabled people. I remember someone with rheumatoid arthritis coming here and visiting me and I visited her in Bradford. She had, with rheumatoid arthritis, paralysed from the neck, she had a great spirit. She and her mother were living in a one bed-roomed house up-stairs in Bradford. It had two little cupboards, one for the kitchen and one for the loo, very little room. A few years later her mother had a stroke and she had to use her long handled fork to bang on the window to attract the paperboy at seven in the morning, who came in and her mother was half out of bed and half in bed and Theresa couldn't get out of bed herself. Because of that case I brought in the need for disabled people to have a telephone, some form of communication with the outside world. You know we had quite a lot of first-hand experience that we could give for that legislation and there's been other legislation since and of course kerbs. But you know, going around London I use an electric wheelchair sometimes, there are kerbs nicely sloped and then you come across one kerb which they've forgotten about, and this is always the way! I must write to the Westminster Council to make that better. They did something outside Westminster Cathedral not long ago and they completely forgot so I wrote to the councillors about how hugely important it was to put in kerbs because lots of people visit around Parliament and need these facilities, particularly for electric wheelchairs because you can tip a manual wheelchair up but the electric wheelchairs won't, they don't like kerbs. So I wrote to the local councillors and they changed it, so communication is very important. But signing places, I saw a restaurant the other day we wanted to go to, we knew that there was a lift somewhere but it hadn't been signed, so we went round and round in circles looking for it and we did find it in the end. You've no idea how many people are trying to find that lift, the lift was excellent in fact, there were two of them, but no sign. So signing is terribly important and of course parking for disabled people. Living, just ordinary living. So many people park in the disabled places and they've got to just make that a bit stricter. So many people are given out badges which sometimes they really don't need because it's a space, and it's so difficult for the helpers if the wheelchairs can't get alongside the car for transferring. You know it's about making people aware all of the time. Sometimes it's such basic things like of course getting onto aeroplanes and things. It's about attitudes, if the right attitude is

there. That's why these sports with all their volunteers and things, there's a good spirit and I hope that will generate out because it's councillors who need it and teachers in schools. Some children have a good school and helpful people but it's so often the head where it can generate down to. I was invited to a school in Watford to give the prizes and there were nine children in wheelchairs. Some of them had scoliosis, you could see it in their backs, and I said to the headmaster "headmaster do these children have physiotherapy?" "No" he said, "there aren't enough of them to make it worthwhile." Well, even if there's one it's worthwhile, this is their life ahead of them and you've got to keep the body as fit as it can be, and with growing children this is terribly important. So there's still lots to be done, you know it's no good thinking it's all going to work, it has to go on. Jack Ashley, who was also in the House of Lords and died this year, he was a huge campaigner, he campaigned for Thalidomides, and they still need campaigning for, it's an on-going thing. So certainly I hope that these sports will make people realise how important it is. I think with all the volunteers it's certainly teaching the volunteers, it's opening their eyes really.