Transcript of MEN1 Patient Film

(Patients giving interviews to camera)

Patient 1: When I was first diagnosed with MEN1, I was shocked.

Patient 2: Just lost and on my own.

Patient 3: Confused.

Patient 1: I felt very apprehensive.

Patient 3: I was bewildered.

Patient 1: And I felt ignorant because I didn't know anything about it.

(Footage of people walking in a busy street.

Narrator: MEN is just one of many genetic abnormalities that can affect people but what is MEN Type 1? Just how common is it?

(Footage of each consultant)

Narrator: Professor Raj Thacker of Oxford University and Dr Stephen Gilby of St James' Hospital in Leeds are leading experts.

(Interview with Dr Stephen Gilby)

Steven: MEN1 is a condition which is inherited down families in a particular way which is loss of immuno-supressor gene which often presents with Hyperparathyroidism but also includes tumours of the pituitary gland and tumours of the pancreas.

(Anatomical cross section)

Raj: The exact instance of this in the population is really not known but around 1 in 100,000 would be a reasonable estimate on current figures.

Narrator: Liz Dent is an MEN1 patient who lives near Harrogate in North Yorkshire. She first started noticing symptoms in her early 40s.

(Footage of Liz in her home)

Liz: I had bloating, I felt very lethargic and I realise now how irritable I was all the time.

Narrator: Terry Green lives in Worthing, West Sussex. He's also an MEN1 patient.

(Footage of Terry outside his home)

Terry: From the age of 10, I was having blackouts, everyday, sometimes twice a day at school. Erm, I would pass out after lunchtime generally, playing football. I used to play football and in the afternoon, I used to wake up in hospital.

Liz: Well my daughter, my older daughter Emily was first diagnosed with this condition when she was at university in Hull.

Emily: It was only really when my periods stopped that I realised it might possibly be something more serious and it was through blood tests that they did when I went to my GP because of that, that really showed up the high levels of hormones that I had in my blood.

Liz: They then put two and two together and that possibly this could be the same condition that her grandfather had, so they decided to test me, genetically test me and my other two children as well and found that we all had MEN1.

(Footage of St James' University and Dr Stephen Gilby in his office)

Stephen: Most tumours associated with MEN (MEN1) are not entirely but relatively benign and so many of the problems that come with MEN tumours relate to the hormones that are produced by these tumours and the affect that they can have on the people with these tumours and so that's an important reason to treat them.

(Anatomical cross section)

Narrator: Parathyroid growths are the most commonly occurring tumour in MEN1. Nearly 90% of patient will develop these growths in the neck causing over secretion of parathyroid hormone leading to the loss of calcium from the bones.

(Interview with Mr Barney Harrison, Consultant Endocrine Surgeon)

Barney: One of the treatments for parathyroid problems is to remove all or nearly all parathyroid tissue and this may result in the patient requiring long term calcium and vitamin supplements. Experienced surgeons will want to visualise all the parathyroid glands at operation because the degree at which it is enlarged determines whether or not it is removed. But in essence, this is safe surgery and not surgery that's particularly prone to complications.

Narrator: Although the symptoms of excess calcium may seem trivial at first, obtaining appropriate treatment is very important.

(Footage of Oxford Centre for Diabetes, Endocrinology and Metabolism)

Raj: If the parathyroids aren't treated and they damage the kidneys, it could lead to kidney failure or high blood pressure and strokes or problems with the bones and fractures such as osteoporosis.

(Footage of Terry Green and family walking by sea)

Narrator: Terry Green had his first parathyroid operation aged 17. He's had more surgery than most.

Terry: I've had 5 parathyroid operations, the first one was to remove one offensive gland but I think they knew in the future I was going to have to have more because the next gland then started to overreact.

(Footage of Liz in her kitchen)

Liz: My parathyroid surgery was carried out in June 2000 and I was told I had tumours on all 4 parathyroids from the scanning and that I would have to have them all removed which did in fact happen. My surgeon was absolutely great, it was carried out at Leeds and I recovered very quickly, actually I think I was out of hospital in just a few days.

Emily: The recovery time was actually quite short; I was quite quickly better and was eating and drinking normally within a very short space of time.

(Anatomical cross section)

Narrator: Another area of the endocrine system affected by this illness is the pancreas. Around 75% of MEN1 patients will go on to develop growths. Most will cause abnormal hormone production affecting the digestive system or the blood sugar balance. If left untreated, some of these growths may become malignant. Treatments for pancreatic tumours can differ depending on the severity and on the location of the growths. Sometimes only drugs are necessary but at other times, surgery is required.

Raj: Occasionally, we do need to go in and take the tumour out.

Stephen: The treatment depends on the circumstances.

Barney: Now this is very major surgery for most patients and involves removal of either some of the pancreas or the greater part or all of the pancreas. In some centres, only part of the pancreas would be removed and the likelihood of diabetes is very low. The risk is though that the rest of the pancreas may be prone to developing further tumours for which they've had their surgery so far.

(Footage of Liz's home)

Narrator: Liz had pancreatic surgery in August 2000.

(Liz walking her dog)

Liz: First of all, I thought I'd only have to have 80% of my pancreas removed because they had identified I'd had four tumours but when the surgeon operated on me, they actually found that the tumours were spread throughout the pancreas so the whole of the pancreas had to be removed.

Emily: Before the operation, I'd had an endoscopic ultrasound which revealed four tumours and unfortunately they were found to be in different parts of the pancreas, one in the head, one in the tail and two somewhere in the middle.

Narrator: Although Liz and Emily are diabetics, this outcome isn't always the case.

Barney: One of the problems for us as surgeons in dealing with MEN1 patients, is we are not sure at this point in time what the best intervention is. The payoff that's best for the patient is the removal of a small piece of pancreas and the removal of a tumour may mean that in future years, they're exposed to the development of more tumours

and the risk from that. On the other hand, with small resections of the pancreas, they're avoiding some of the complications of having the greater part of having the pancreas removed like diabetes. But keyhole surgery can certainly be used for removing pancreatic tissue but generally speaking it's best used when the surgeon and the doctors caring for the patient are sure before the operation what exactly is going on. If the surgeon is unsure as to the extent of the changes to the pancreas then the more traditional approach to the pancreas is required and that means a bigger cut.

Raj: In those instances when the whole of the pancreas needs to be taken out, then clearly we need to replace our hormones. One of the big consequences is diabetes so the patient will have to go onto insulin because there will be no more insulin made by the pancreas. The other thing that the pancreas does is it makes a lot of other enzymes which help us digest our food.

(Terry in his kitchen)

Terry: I've had three pancreas operations, I have to take insulin injections, I have to take tablets when I eat.

(Emily walking to restaurant)

Emily: It does affect my daily life in some ways; I do have to make sure that I eat properly and I have to make sure that I do take my injections when I need to.

(Footage inside restaurant-Emily writing her food diary and injecting insulin)

Emily: But they've actually become part of everyday life and I find that that has actually become normal for me and actually a lot of my friends now are in a position to help me with that. I quite often, over a meal will say to them, "Right, how much carbohydrate is this? Tell me how much it is. How much insulin should I be taking?"

(Liz walking her dog)

Narrator: Whilst Terry and Emily use traditional injections, Liz has a novel but increasingly popular way of managing her insulin levels.

Liz: I was suddenly a diabetic, my management wasn't brilliant. Everybody had mentioned, I'd be better off with an insulin pump and I'd never heard of one of these before.

(Shot of Liz's pump)

Liz: My insulin pump is a small unit looking very much like a mobile phone actually; it's just fitted to my belt. It's very comfortable, I never know that it's there all the time because you initially put the needle into your stomach, you pull the needle out and a little plastic catheter is left inside so you never feel it at all.

(Footage of Terry at home checking blood sugar and how monitor works)

Narrator: But as a diabetic, it's necessary to keep your blood sugar levels in balance.

Terry You work out a balance by checking your blood sugar levels. It's just a push button device, looks a bit like a calculator. You put a sensitive stick into it; it tells you when it needs the blood. You prick your finger, put the blood on the monitor strip and after about 30 seconds, it tells you what your blood sugar is. The blood monitor's so simple. I can't even describe what I do, it's just automatic.

(Anatomical cross section)

Narrator: The third area that MEN1 can affect is the pituitary gland located at the base of the brain, just behind the nose. About 30% of patients will develop a pituitary growth which will require some kind of treatment.

Raj: The pituitary tumours, it depends again, what they are

Stephen: It might just mean going on medication, no surgery needed.

Raj: We have a lot of medical treatments; i.e. tablets that we can use to keep these under control and treat them and they are not like chemotherapy. These are not tablets that are going to make the hair fall out and make individuals feel ill. They are much more benevolent tablets in that way and we can control things very well.

Stephen: In many cases, the prognosis is good, the treatment is very effective and the expertise is there to give the best possible treatment to patients.

Emily: I have a pituitary adenoma which as I understand it, it was a macro adenoma which is a large tumour but it is benign.

(Footage of Emily writing)

Emily: I've been taking tablets for that which I take once every 5 days and that has now shrunk the tumour down and lowered the level of prolactin also.

Raj: Some tumours can't be dealt with, with tablets and so we have to undertake surgery. Now if the tumours are small, the neurosurgeons are very good and skilled to actually go through the nose, through the nostrils actually, so you don't even see a scar on the outside. They go through the nostrils, up the nose and take the tumour out. If they can't do it that way, they will actually do through the roof of the mouth and again, there is no external scar.

(Footage of sea, Terry and family)

Narrator: Terry developed a pituitary tumour which needed surgery using the nasal approach.

Terry: I went away from the doctors thinking I've got a brain tumour, I'm going to die and my family, I'm sure were thinking the same. It turned out that within weeks, they'd removed this tumour from my pituitary gland and it was a case of going to sleep and two or three hours later, I was up watching the FA Cup Final! It was so simple for me, I'm sure it was a great difficulty for the doctors (to give them a bit of credit!) but yeah, it was all over and I couldn't believe how simple it was in the end.

(Footage of patient in hospital with doctors)

Narrator: Suffering from MEN1 can appear daunting at first but with the latest specialist knowledge and often very effective treatment, things are not always as bad as one would first imagine. Patients find it helpful to have a positive attitude and to play an active role in managing their conditions.

Emily: I feel the outlook for me is very positive. I keep a track of all my treatments, all my scans and blood tests. As long as I am regularly monitored, hopefully if there was anything else to happen, it would be found quite quickly and the relevant treatment would be given. You take each day as it comes and you just hope for the best which is really all you can do.

(Footage of Liz and her dog)

Liz: I think you have to keep MEN1 in perspective, there are worse things. As long as we know what's happening, we're in control, we know all of the options available to us, we can do pretty well and all the time, there are advances.

(Footage of Liz shopping)

Liz: I'm very positive and that's what I am to my children as well.

Stephen: It's still important to recognise that these are tumours with a long term, what we call morbidity or mortality, in other words, long term consequences so effective management of the tumours as early as possible is a very important part of the management of patients.

Barney: Ideally, the patient should be looked after by a group of doctors who can provide a whole range of treatments for any part of the MEN syndromes. Once the patient had been diagnosed, then I think they need to be referred to a specialist centre where there is an MEN clinic or something of that kind.

Raj: I think one of the most important tasks we have is to provide very strong assurance to our patients with MEN. This is a chronic illness not a terminal illness like other cancers. These tumours are slow growing and with early detection and proper management, they can be treated very, very well. So, our patients live for a long time, into their 70s and 80s and have a very full and productive life.

(Footage of Terry on his motorbike)

Terry It's fair to say, I'm a born again biker. I look forward to anything I can just throw myself into. I appreciate life a lot more these days. The more I can do, the more I enjoy it.

(Footage of Terry on a plane)

Terry: Leaping out of planes is one of my favourite pastimes.

(Footage of Terry's sky dive)

Instructor: Hey! Hey! Hey! Alright! Hey buddy, what do you think of that? Pretty good?

Terry: I'm breathless!

Terry: I'm not a risk taker but I like adventure!

CREDITS ROLL