One of them is Brett - Transcript

“Can you eat two sausages, Mark?
- Yes.
- What about you, Carl? Two for you, darling?
- Yes.
- Give your plates to Daddy.
- That'll do, Mark.”

This is Brett's family.

“He said, the other day... Err...He was pretending to be his father. He said: ‘I'm Peter Nielsen and I've got three sons.’ And I said: ‘Oh yes? And what are their names?’ He said: ‘Well, one is Mark, and he teases. And one is Carl, and he cries. And one is Brett, and he's got no arms."

THE SOCIETY FOR THE AID OF THALIDOMIDE CHILDREN PRESENTS

ONE OF THEM IS BRETT

Brett was born in Australia four and a half years ago. Now, he lives in London where his father works as an engineer. He and his brothers are perfectly healthy. And so are his parents. There is no history of illness or handicap in the family. Brett was born without arms because, when his mother was pregnant, she was given tranquilizing pills containing Thalidomide. She was one of 10,000 mothers all over the world who had the same experience. At his birth, his parents were deeply shocked. They faced a choice: either to feel sorry for him and for themselves or to cope and to help him cope.

“We felt that, rather than treat Brett gently, we should make every effort to treat him as near as possible as a normal child. Protect him from the obvious dangers, but he must not be protected anymore than was absolutely necessary, because he was going to grow up in a normal world where people will say hurtful things, where, whilst he may be quite an adorable little thing whilst he's a baby, he won't be very adorable when he's 15 or 18 or 25. So he must compete with others.
Of course, we felt sorry for him while he was young but as he grew older and was quite happy, there was no need to feel sorry. Why should one feel sorry for a happy person?”

“Don't touch me! Don't!”

“He sees the world not quite through rose-coloured glasses but he thinks people are mostly very kind, very good people. He's inclined to speak and smile at almost anyone. People are very sympathetic towards him because he's a reasonably pleasant little boy of four, and who, unfortunately, has no arms. Brett thinks most people in the world are kind, isn't that great?”

Brett is quite bright for his age but when he was born, many people, including the doctor, somehow expected that, because he had no arms, he would be mentally handicapped as well. In fact, it had the opposite effect.

“These children seem to be using their full potential. Now, I believe that most of us coast along using about 60, 70 % of our potential. But, these Thalidomide children, right since the

birth, have had to try very much harder than the normal person at everything that they do. It's become a way of life with them, and I think they will continue to do that.
And even those who have, say, below average intelligence, will probably do better in many ways than normal children, physically normal children who have the same IQ, because it is what they do with their intelligence that matters."

"Wipe the floor."

There are however, many things which Brett cannot do for himself.

"I think, too, there's a certain amount of resentment at the amount of time and effort one has to give to this child. I felt very guilty about it. I used to get so annoyed when he would ask me to, not ask, demand, that I should do this and do that, when he would scream so much, but because the child was so handicapped, it seemed even worse to me to feel resentful."

Brett's mother realised that her resentment was normal for a young woman with two other children and so, stopped giving in to him automatically. But she also saw that Brett was not just crying for help. He was crying for more independence.

The Nielsens, like many other parents, had already been through a frustrating series of hospital visits. Thalidomide problems were new and so complex that most doctors were caught unprepared.

"Hello, doctor, how are you?
- Very well, thank you."

But today promised to be different. This hospital had offered not just advice and sympathy, but an arm. There are, of course, artificial arms and hooks already worn by thousands of people, like war veterans. But most Thalidomide children can't wear them. Their shoulders are not strong enough to make them move. They need arms that power themselves. So scientists worked frantically to give these children a special arm. Its power comes from compressed gas kept in a cylinder on the child's back. And it's controlled by switches under the chin. First produced in Germany, it was successfully introduced to Britain by Lady Hoare for further development in this country.

"I think this is as good as any at the moment. The Heidelberg Arm. With this, and the training of the child, we can, at the present time, with this arm, already obtain three types of movement. One is the rotation of the wrist, which the child can produce by pressing this switch. The second one is the flex of the elbow, which again, the child can produce at will. And finally, there's the grip, like a forceps. Now, the combination of these imitates the movement of a normal arm."

"Put your head right back, Brett.
- Let me see if you can press it. You can press it on one side, it comes up. If you press it on the other, it goes down.
- Now, you press it with your chin for a minute. That's it. Yes, lovely."

The movements are simple but the apparatus is complex, especially for a little boy or girl to live with. It will take 12 days just to fit the jacket properly. And, as he grows, Brett must return for a new arm every six months.

“Not that way.
- There.
- (...)
- Right.
- Can we go now?
- You want to spin around on the chair first? Better ask your friend first.
- You've been a good lad. Give it a good swing.
- I don't like it.
- Alright?
- Yeah.”

“Working?
- It's stiff.
- Try the elbow. That's a shot. Come over here. Maybe try the others, other switches and see if they work too. That's right. That's right. Good. I think it'll work if you try hard enough, if you keep trying. Come on, you try with this one. Close it. That's it. You see, you can. Now you can repair your bike. That's the boy.”

Like a baby, Brett must start from the beginning and learn what his arm can do and what it cannot do. It will take much longer than with a real arm, which has no switches and will not slip or jam or run out of gas. But Brett wears it even when it doesn't work. For just wearing it makes him feel better, especially in public. For these children, the most serious handicap is not physical, it is social.

“When Brett was a tiny baby, I used to take him out to the shops and the clinic and whatnot, as much or possibly more than I used to take the other children, because I thought: ‘Let him get used to being stared at, and poked’, as some people do, ‘right from birth.’ Better to be used to half a dozen stares every day of the week, than to just suddenly get half a dozen every Sunday. Old people I find to be the most difficult to handle. Or sometimes people have come straight to us and said: ‘Did you take those drugs?’They somehow think that one is a drug addict, a narcotic, who takes narcotics. And so they think that these mothers have brought this on the child themselves. And women have come up on the street and said: ‘You ought to be ashamed of yourself, look what you've done to that poor little child.’
For quite a long time, it would hurt. But mothers who keep their children at home, so that they may protect themselves and the children from stares and from the unkind remarks, are really making the burden far greater because the child must come out into the world someday.”

Unfortunately, for a handicapped child, the outside world includes relatives and friends, for many Thalidomide families felt themselves shunned and isolated. Seeking advice, they were only offered a screen of embarrassed sympathy. So they sought solutions among themselves.

“We formed, while we were there together, a world organisation for all parents. And we are now representing over 6,000 Thalidomide children that we know of. Since the meeting, we've already discovered that there are several hundreds more in smaller countries, and the whole thing is growing all the time.”

“We joined the Society because we wanted to meet other parents, so that we could compare notes. Not only successes, but failures. Really, the Society was formed not just to raise money, not just to pool ideas, but so that people could share their problems because trouble shared is trouble halved.”

“I learnt, again in Germany, that they know exactly how many children will be of school age next term. They know exactly how many will be going to school next January. They are so well-aligned for what's going to happen in the years to come that we're going to bring our own records up-to-date.
They know what transport they need to get the children to the hospital. They've been in touch with the headmasters, to see that the children are going to be taken into the schools. You know, they really are on the ball about this. They've considered it five years from now. And then after that, they're going to consider the problem of work.
- Mike, is this the German government who are doing this?
- Oh, no, this is the German parents. This is where, again, we've got to look ahead, to much more concern with them than we have up to now. I know that we’ve all got our individual problems, but a collective problem has got to be taken, and Peter and Joan Hart and the rest of the council, the rest of you have got a lot of work ahead of you, I’m afraid.
- I think we've helped in two cases already. The children are coming up to nursery school, not junior school. And I think that behind the scenes, one can do an awful lot to select the schools where the children are going to be happiest.”

“ In, out!
In, out!
Like a jack-in-the-box!
In, out!
In, out!
Like a jack-in-the-box!”

“Now, I want you all to come and sit round because I'm going to tell you all about Brett before he comes to see us. Sit down so you can hear me, come here.
Do you remember me telling you about Brett last week? Remember me telling you that when his mummy made him, there wasn't quite enough to make arms? And how lucky you are that when you were all made your mummy managed to make arms for you?
He's coming to see us this morning with his special arm.”

“Hello, Brett! How are you this morning? You’ve come to see us at nursery school. Good! Come and sit down here. Would you like to sit at this table here? Do some work at the table. You don’t want to sit at this table. Come along.”

“He's grown up with the fact that he hasn't any arms, and he accepts things so completely as they are. And he doesn't mind if the children say to him: ‘Where are your arms?’ He'll answer them quite sensibly. The children seem to get on with him very, very well and tolerate things that he can't do, and make allowances for him. The children accept these things if you explain to them why it happened. As they grow up, they won't look at other people and be horrified by things so much. They'll learn to accept them. Because there's an awful lot of deformity in the world.
It’s the parent who’s much more worried than the child about it. I suppose it's just an in-born fear of any kind of physical deformity. Some people just can't accept it. We've only had one who did show a slight aversion. She was very sorry for Brett, but she wasn't sure whether she wanted her child to mix with him.”

“When he had his arm fitted, he was very ready to try to use it. In fact, he insisted until it got uncomfortable. And I'm hoping that the two arms will be more satisfactory. He can then be with a normal class of children and learn to write, and to use his fingers such as they would.”

“Let’s have it standing up like this so you can manage to put it in here for me.”

“Real school children can be very, very cruel, you know, to other children. Little ones like this will accept him. When they get to school, they start to criticise each other. And I think he might find it quite hard if he hadn't his arm. I think he's a very intelligent child. It'd be a great pity if he didn't remain with normal-thinking children.”

“Brett has to go to school in... now three months. We are very concerned about his inability to handle his toilet needs. He hasn’t yet been accepted by the local school. The headmistress is very reluctant. She's been making up her mind for months about it.”

“Listen. How about we put this sleeveless pullover on, darling? You haven’t been...
- No!
- You're forgetting how to use an artificial arm now.
- I'm not!
- Come on. Try it on with this sleeveless pullover, and then, see how it is.
- No!
- You'll forget all about it.
- It hurts with the sleeveless pullover on, too
- Where does it hurt?
- On the shoulder
- How about if I put some more padding in here? Do you think that'd be alright?
- No, that won't help it.
- Why not?
- Because... if... I don't know!
- Well, we'll just have to see if the doctors can make something better, hey?
- Alright.”

So, research moved ahead. Lady Hoare brought back from Russia a bio-electronic limb. A major development which has altered the lives of the four arm amputees who've worn it. The Nielsens went to see it demonstrated.

“That's quite nice. It looks like a hand, doesn’t it?
- Yes. This is basically made up of components that came from Russia. And the arm itself has been made in this country. So, basically, it's a British arm with Russian components.
- With Russian components. Yes, indeed.
- This is the relay system and a dry cell battery.
- A rechargeable one, is it?
- Yes, this is rechargeable.
- How long will this battery last?
- Well, they say it should last 3 days.
- It depends on how much you use it, obviously.
- That’s right. And it can be charged overnight.
- And I see you have two pickup controls there. How does this actually operate?
- This is worked by two electrode contacts in the socket.

- It works like this: when you, you pull your hand round, well, you're using the muscles here. When you open it, you pull it back the other way. Basically, that is it. The patient has only got to think about this. There's no physical effort.
- Is there any sensitivity in regards to feel or pressure with it?
- Well, the patient says that when they’ve got hold of something, they feel that they've got hold of it.
- They can actually feel this being transmitted back to the...
- This is what they say.
- But to my mind, at the moment, the thing I like about it is, it's a nice, relatively smooth, controlled action.
- But it only provides the one function, doesn’t it? Gripping things and picking them up.
- Once a patient really gets used to this, he can close it in stages and he can open it in stages.”

This limb will be of so greater value in the future, as soon as it is adapted for children.

There are many children, besides Brett, who need help. Like David Bickers who was with his mother at the hospital the Nielsens visited.

“... by sighting the valve controls right there, and then use the, at the moment, the gas powered equipment. And that's so promising for the children if we can get the right pickup points. Then I think we could use them for that purpose with the other types of equipments, along the lines of the Russian one.”

“Err... What can you do, David?
- I do painting.
- You do painting?
- Toys.
- Yes.
- Drums.
- Yes.
- Do you like using your arms? You do.”

What can be done with the limbs they have? Most of these children have operations to free constricting skin and exercises that stretch tiny fingers and legs to make the utmost use of them. For every ordinary event in living is a challenge to a handicapped child.

“One thing I think is important, is that mothers should make it perfectly clear to a child likely to be teased, that they will not grow arms. I've heard children ask their mothers about their arms:
‘When I'm a big man, I'll have arms, won't I?’ And the mother deliberately avoid it. ‘Let's come into the shop and we’ll buy some sweeties.’ Now one day, that child is going to suddenly be faced with the horrible fact. ‘Why didn't you tell me I’m not going to have any arms?’ And I find it terribly important that they know the absolute truth.”

The search for new arms helped Brett's parents with their own handicap: self-pity which inevitably haunts any family with a crippled child.

“Because, then, one can see the, our own child's handicap from the right perspective. It isn't so grave. Here are other children far, far worse off. Yet, we are feeling so sorry for ourselves and for our child.

If the mother realises that there are hundreds of other mothers with far worse problems, then one doesn't feel alone.”

And the children learn this, too.

“What's this? What's this?
- Go to that boy up there. Go give it to him.”

These boys have a spinal defect, which will keep them bedridden for the rest of their limited lives. In Britain, 800 children are born every year who suffer from the same handicap.

“What colour?
- Well, it’s the orange one.
- What colour's mine?
- Yours is the white one.
- Say bye to Ken.
- Goodbye.
- Goodbye, Ken.
- Come along, Mark.
- Goodbye to the boy.
- Goodbye.
- Come on, Brett. Time to go home.”

“Feel the weight of that, Mr Nielsen.
- My God, that's really surprising, isn't it? You feel that, Barb.
- Very heavy, indeed.
- Tell me, what type of hand do you normally use? A terminal device, or...
- A mechanical hand controlled with a control board on the inside.”

The search led the Nielsens to a factory where the arms are made. It has 10,000 clients on the National Health Service in Great Britain alone. This visit helped to calm their chief anxieties about Brett's future. What job could he hold? What about marriage? For one third of the employees of this factory are handicapped themselves.

“This is the progress department where the limbs...”

Through having Brett, the Nielsens discovered the meaning of the word "handicap" in day-to-day living. Feeding oneself, washing, brushing one's hair.
The Nielsens' search began 12,000 miles away in Australia. Powered limbs are so new that they had to come all the way to England to find them. The search is not over. The movements are still frustratingly simple, but some children older than Brett have already learnt to write and to feed themselves, and thus unlocked the chains of dependence that bind their future.
This is the challenge. It is no less difficult than what has been met before by millions of handicapped people in separate, personal struggles.
Like Brett's.

THE PRODUCERS WISH TO THANK ALL THE INSTITUTIONS AND DOCTORS WHO GENEROUSLY GAVE INFORMATION AND HELP. THEY, THE MINISTRIES OF HEALTH AND EDUCATION, AND THE LADY HOARE THALIDOMIDE APPEAL,

ARE MAKING SURE THESE FAMILIES ARE NOT ALONE. THEY PROVIDE PERSONAL HELP, THROUGH WELFARE WORKERS AND EDUCATION OFFICERS, AND MATERIAL AID, IN THE FORM OF NEW CENTRES AND SUCH RESEARCH ACHIEVEMENTS AS THE GAS-POWERED AND BIO-ELECTRONIC LIMBS.
OUT OF THE TRAGEDY OF THALIDOMIDE IS COMING A DEFINITE GOOD, OF PERMANENT BENEFIT TO ALL TYPES OF HANDICAPPED CHILDREN.

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