

COMMUNITY FOCUS

“Take your shots and take what comes”: Rex Jepson

Steve Chaplin

Rex Jepson was born in 1920. Aged 97 when he spoke to Haemnet in July 2018, he is the oldest man with haemophilia in the UK. He has experienced – survived might be a better word – the evolution of treatment from life-saving blood transfusions to weekly prophylaxis with recombinant clotting factor. Severe haemophilia A has brought him to the brink of death and it has had a profound impact on his life. But he has never given in. He says, “Don’t ever take the approach that ‘Oh dear, I can’t do it because I’m poorly’. You might as well give up, pull the lid down and go now. You’re not poorly, you’re just different.”

GROWING UP

When Rex was three, the family moved from Nottingham for work at Markham Main pit in Armthorpe, a village outside Doncaster. Rex’s father worked at the coal face – hard labour for low wages. Rex remembers him as a gentle, kind man with beautiful handwriting, better educated than his fellow workers. The family, and the mining community they lived in, was poor.

Rex’s haemophilia was first recognised when he was circumcised (he knows of no family history of a bleeding disorder). The diagnosis led to the first of many far-reaching effects that came from living with haemophilia: his parents decided to have no more children in case they too were affected.

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Rex Jepson, pictured on 3 August 2018. Born in 1920, Rex was 36 before he received his first treatment for a bleed with fresh frozen plasma. He has lived through a period during which the management of haemophilia has been transformed beyond all expectation

The wider impact of haemophilia became apparent for the first time when Rex was about four years old, after a visit to the sweet shop.

“We ran back and I stumbled and I fell on my knee on the kerbside – and, of course, got up crying. I went in and [my mother said], ‘Rub it, rub it, rub it better.’ But it was my first bleed. But nobody knew what it was...”

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"Nowadays what you do for a bleed is pack it with ice. I'm talking now, remember, 1920 – there was no question of ice. And in any case, nobody knew what was the matter with me. I'd fell on my knee and it was swelling up and it was ever so... I was in screaming pain, and I knew I was because they said they could hear me in the next street..."

"The first known bleed was a knee at about four years old, painted with iodine – God help us. It's a wonder I didn't go stark raving mad."

Until then, the family understood that haemophilia was about bleeding, but no one had told them about joint bleeds. With no treatment, Rex remembers days in extreme pain from swollen joints. Someone would be dispatched to the pharmacy to buy analgesics –

which, in those days, meant aspirin. No one knew that it delayed clotting too.

Despite such traumas, Rex's parents did not stop him playing outside with his friends – so the joint bleeds and muscle bleeds mounted up.

"I was like a young hobo, that's what I was. And of course, in the process of this, I could produce myself an arm [bleed], a leg [bleed] or whatever. I could decide that I could jump that ditch – if Tim [a pet dog] could jump it, I could jump it. And of course, there goes an ankle. And that's the way it was. So, life was life, and you took the knocks as they came."

Rex has captured this time in a poem, 'The Early Years' (shown below). He hasn't got round to writing Chapter Two (so far).

The Early Years

*Listen you kids of five and twenty with nurses and doctors and care aplenty
Listen up I say and let me tell thee what it was like in 1920.
Cos when I was born the doctor said, "Now make no plans to see him wed.
He has what's called the royal disease, he will have awful pains and big fat knees.
His teeth will ache and they will bleed and I have nothing for his need.
I truly think he won't see seven – by then I fear he will be in heaven."
This reet upset me mam and dad, who said, "We love our little lad.
We'll take him home and get him strong and hopefully we'll prove thee wrong."
So home we came, to start the fight and then we got our first big fright.
I got to the gates – that's them that's pearly,
And Peter said, "Tha can't come in, tha here too early.
Tha' can't come in, tha' not on me list So get back home 'afore tha' missed.
Now don't thee frown and pull a face. When it's thy turn, I'll find thee a place.
So get back now – and don't take hours – or thee mam will have gone to order flowers."
So back I came, back to the fight, but that young doc was almost right!
I must have been a lucky lad to get the parents that I had
A caring, loving gentle mum,
A dad who said, "When I'm out t'pit, I'll do me best to keep thee fit.
We'll walk in woods and fields with dogs and see the birds and little frogs
But them knees o' thine are just not strong, that walk to school will be too long.
So Mam and me will buy thee books and teach thee how to read
And buy thee pens and copy books so you can learn to write."
We did all that, it worked out fine and we beat the odds, I'm up to nine
About what came next I'll tell to you, so watch this space for Chapter Two.*

With his mobility limited, Rex remembers using crutches and borrowing a wheelchair from the Miners' Welfare Association.

"Father used to take me round the village in the chair. Being a miner, they had all sorts of facilities at the mine, of course, and there was a chair or two available for just borrowing, literally. He would borrow it for a period of time and take me out in the village in this chair when I'd got an ankle or a knee. And then I'd be alternating between that and getting my crutches for just around the house."

Rex did not go to school, which was at the other end of the village, until he was nine or ten. His father bought him copybooks to practise writing and comics and books to learn to read. There were other, subtle ways in which haemophilia marked him out as different. Poverty was so widespread that new clothes were unaffordable, so the children would wear hand-me-downs from their older brothers and sisters – except Rex, who was an only child:

"They'd be wearing cast-off jumpers that their brothers had worn. I'm talking now when families were six and seven boys and two girls, miners' families, and the clothes would go up and down the scale. So, Diddy [a friend] would be wearing an old jersey, probably too big; he'd probably have boots on with no laces but bits of string in; his toes may or not, I can't remember, but his toes could have been in or out – and that's what he would be wearing."

"I'd got a proper suit on. I'd got a collar and tie, I'd got a shirt with a tie, I'd got my leggings on, I'd got proper shoes, shined till you can see yourself in them – that's my mum – and a cap on."

When gangs from adjacent streets came face to face, he would be excused from the ensuing fight:

"I can see Diddy facing up to this guy and saying, 'Tha doesn't touch him, tha knows. He's only got one skin.' And, of course, he'd look me over and I would be a good reason for a punch-up."

When Rex was 12 his father learned of a charitable organisation whose benefactor seems to have been

Winifred Anna Cavendish-Bentinck, the Duchess of Portland (1863-1954). She supported Nottinghamshire mining communities by building alms houses, paying for medical treatment and organising cookery and sewing classes. Her good work was recognised by the Nottinghamshire Miners' Welfare Association, which petitioned the King to award her an honour. She was made a Dame of the British Empire in 1935. Thanks to this benevolence, Rex was sent to a private clinic in London for three months under the care of Sir Aldo Castellani, a specialist in parasitic diseases such as malaria. It was presumably his expertise in blood disorders such as haemolytic anaemia that prompted the referral, but he could not help Rex.

"And because there were no other kids to play with and it was a sort of very sedentary experience, I never produced a bad arm [...] I never produced anything for it. They were quite disappointed, so to speak. Blood tests were taken and all that could be suggested was, 'Put him on a regime of taking parathyroid and calcium tablets for the rest of his life.' That was that."

Schooling was abruptly ended by an accident which was to have lifelong consequences.

"I finished school, by the way, by falling off my bike. At 13 or 14 I fell off my bike and cracked my knee up, and that was the beginning of the knee going wrong – it never, never got better. It never got better. So, I was finished school, that was that. And I was in plaster with that knee, on and off, for quite some years, into my early teens."

"Then in my later teens... By now it was getting to 1939 and I'm on and off crutches with that knee. At that point, my knee had contracted to a point where I was walking on my toes, sort of thing, with the crutches."

BIKES, CARS, MARRIAGE – BUT NO TREATMENT

Rex's father retired from the mine in 1939 ("His back went, like a typical miner") and he found a job as the school caretaker. This put Rex in touch with the local Air Training Cadets (ATC) and led to a spell teaching aircraft recognition and Morse code. Rex was good at this but could not join the ATC because he was disabled, and so was denied the opportunity of a flight that the cadets enjoyed. But that disability did not stop him cycling.

"I'd got one pedal off and I'd got my cycle now on fixed gear. I'd sling my crutches on the handlebars and strap them at the back wheel, and I cycled all over the place. And that's how I used to get about, on my cycle, and take my crutches with me. That's how I moved about... And I could do 15 miles – makes me shudder now thinking about it – I could do 15 miles on a Sunday, one pedal, to go round the local aerodromes and have a look at the aircraft, and I thought nothing of 15 miles."

Anyone who has ridden a fixed gear bike will know it can be hard work with two good legs. It takes special commitment to ride with just one.

"A blacksmith friend of mine made a bracket; my foot rested on a bracket, and it was clamped on the frame. And my crutches were down the side with a strap at the back, on the handlebars and back. That was that. Then I gravitated from crutches to one stick, back to one stick, when I built myself a shoe. I was a modeller now, so I made a shoe that I could walk in. It was not brilliant, but it was fair. So, I could walk with one stick and my shoe, so that was a move up. But even then, I had to revert occasionally to my crutches."

But it wasn't long before cars made their mark on Rex's life, beginning with a Ford Popular costing £145 and culminating in a career on wheels – first as a taxi driver, then a driving instructor. Haemophilia had little direct impact on these jobs, though instructing was interrupted by a fall that put Rex back in hospital.

"Coming out the office on the last bit of snow in the February of '54, I put my stick on a bit of ice, went down, put my knee underneath me and bashed my knee up – same knee. So, that was me into hospital, in plaster, toes to hip, toes to groin... That kept me in hospital for quite a long time... When I recovered, I went back to being an instructor. I went back on two sticks, actually, because I was walking... it wasn't good. It had shortened my leg a little bit more."

By now, Rex was married to Violet. To this day, modest as he is, there is still something he doesn't understand.

"Why me? I often ask myself, why me? All these big guys. Why me on crutches? Why me? I'll never get an answer."

Again, the impact of haemophilia reached far beyond Rex himself. Like his parents before him, he and Violet agreed they would not risk having a child with haemophilia in a world that offered no effective treatment.

CLOTTING FACTOR, FROM PINT TO VIAL

Rex was 36 before he was given a treatment that would restore his clotting factor levels. The treatment for severe bleeding episodes was blood transfusion, though whole blood contained a low concentration of clotting factor. It had been known since 1916 that infusion of fresh human serum would shorten clotting time in someone with haemophilia, and in 1936 a precipitate of whole human blood was shown to lower clotting time to within the normal range. Rex's first exposure to this treatment came in 1956, with a life-saving infusion of fresh frozen plasma:

"I'm in with a haematoma and I'm dying – there's no messing about, it's been going for some time and it won't stop and I'm definitely going. I'm weak. And they said, 'He'll have to go into hospital. We've got some... there's some new stuff.' I remember what the doctor said, 'We've got some new stuff that they're trying that's at Sheffield. They're sending it from Sheffield. We'll take him in an ambulance into Doncaster.' And I'm very 'Urgh... urgh...' you know. At that point, I've lost a lot of blood."

"This milk crate, to all intents and purposes, came and was put on the table at the end of the bed, with all these bottles in, frozen, absolutely deep frozen solid. And the sister comes to the bottom of the bed and says, 'This is the stuff we're going to give you when it's unfrozen. You'll have to wait – it's going to be a while.'"

This was a new approach for the doctors too:

"When it had unfrozen, along came the doctors. I'm a bit bleary-eyed by now and they know I'm not going to be around much longer. So, the stand was put up and they both came storming in, housemen: 'We're going to give you this stuff.' And they used an ordinary blood needle, which is quite big, actually; you only need a

very small one. So, one of the housemen put the doings on and he can't get in a vein. And I'm watching what's happening and I'm really, really... and they can't get in the vein. And the other houseman said, 'Look out, let me have a go.' And he got it in with one go; used a different vein, went in. Opened the bottle – you're suppose to let it drip in, about 40 minutes to take the bottle in – and he just opened the cock and let it run in. They put one in – it didn't kill me, nothing happened instantly. But then he took that down and put another one on the drip, and many more. And, of course, that was my first time – and this would be '56."

There was no doubt that fresh frozen plasma was life-saving and it marked the beginning of on-demand treatment for Rex, though it meant an hour-long drive to the Royal Infirmary at Sheffield (there was no specialist haemophilia service there, it was simply the nearest hospital stocking the product).

"So, once I was back out working, if I'd got what I knew to be a bleed... It's a bit subtle. If you know you're going to have a bleed in the joint, there's a subtlety in your body that tells you so. There's a feeling that's not right. It's not very scientific, that, but you know it's wrong. So, I would ring home, tell Violet, 'I'm going to Sheffield, I'll have to drop my next lesson.'

"[...] You'd go in and check in and there'd be a message left for you at the gatehouse, sort of thing: 'Go to ward 10. Doctor will see you there.' So, you'd drop your car wherever you could, go to ward 10, and they'd either be waiting or very shortly get there – probably waiting or they'd set it up ready. Forty minutes to put it in, and if he decided I needed another one... He said, 'Is it bad?' I said, 'I don't know, but it's beginning to feel a little bit...' It might take one or it might take two. One was usually enough. And then it was back home and back to work."

That remained the gold standard of care until 1965, when research by US scientist Judith Pool led to the development of cryoprecipitate. This revolutionary product meant that clotting factor from many units of blood could be provided in a small volume of infusion containing enough Factor VIII to control severe bleeding and cover major surgery. Treatment was still



Image: Rex (centre, back, wearing glasses) on drums with the Blue Rhythm Band in the early 1940s

on demand and still required a trip to the hospital. However, the next ten years saw refinements in formulation, notably the introduction of freeze-drying, that paved the way for home treatment, which Rex began in 1978.

Rex's wellbeing did not entirely depend on treatment: people with haemophilia are advised to exercise and, for Rex, that meant playing the drums.

"...in actual fact, it's the best thing I could have done, because both arms were being used, both ankles, both knees. All the doctors, particularly at Sheffield, said, 'Great stuff.' So, that was a bit of therapy. I actually played until I was around 83/84. I was doing Thursday nights at a local club with a quartet. One or two decent recordings. So, that was another one and the same thing applied. If I had a bleed, I had two or three drummer friends, and I could ring one of them up and say, 'I've got trouble. I can't do tonight, tomorrow, whatever. I've got a bleed. I've got an arm' – that's all I'd need to say. 'Yeah, I can do that,' he'd say, so I'd got that covered."

"Really, what it was now... there were four things, really. I'm teaching, I'm drumming, or I'm deep into my big interest now – pistol shooting. One of my pupils took me pistol shooting and that was it – I'm hooked on pistol shooting. So, I'm shooting automatic pistols. Or I'm in bed with a bleed. That was my life, that was it. From then onwards, that was how it was. Those four things were virtually my life."

HOME TREATMENT AND HEPATITIS

Home treatment was "the best thing that ever happened", Rex says.

"Well, the longest period I ever went without having to treat myself for something was about five months – that was a record. On the other hand, I could do it one week and need it again that same week, later on in the week, for something else. You didn't know – it just happened. But I didn't get spontaneous bleeds into joints; I'd always got a cause. I always knew that if I cracked [myself], 'Ooh!' on the table, I knew that wanted treating.

"Now then, I would be very stupid at times. I used to get a first-class rollicking from my sister, Sister Farnsworth, at Sheffield. Sister Farnsworth and I had been together about 29 years – she was the haemophilic sister there when I first went. If I had a bleed at home and she knew I hadn't treated it, early days, I used to get a roasting, because of this 'hoping it'll be alright' business."

Rex's long familiarity with joint bleeds has given him a hard-earned awareness about the difference between the pain caused by bleeding and other types of pain.

"Yes, it's a different thing altogether. It has this aura that is inexplicable. You can't... it's just you're aware that your body says... you have a feeling in that arm that doesn't feel right. And you have to accept that. Over a period of time, you begin to know what that means – you've always known. And if you get that [feeling], at that point, it would be very sensible to give yourself a dose of Factor VIII; it wouldn't go any further. Now, if that was genuine, it would be a while before it showed; maybe the following day, even, and then you'd have to treat it. And that's when I would perhaps say, 'Oh, it's only a little one. It'll be alright. It'll go away' – which was totally stupid."

By now, Rex was enjoying the independence that came with self-treatment, but it required a down-to-earth approach that wasn't always shared by his fellow band members.

"I was giving myself a transfusion on the back kitchen table one Sunday evening, ready to go on this gig, because my elbow had bruised a little bit. I could sense that things weren't right and I was going to treat this one – I'd learned a bit more sense by then. And I was just treating it, William walked through the conservatory door, straight

into the kitchen, 'Aah!' and literally, literally fell back into the chair in the conservatory. I finished what I was doing. 'Ooh... Ooh...' he said, 'Ooh, I feel sick...' And he was needle-phobic. It really shattered him, absolutely."

In the 1970s, for the first time, people with haemophilia had access to an effective treatment that enabled them to be independent and live an essentially normal life. But safety had been neglected. In the words of the Haemophilia Society:

"These new treatments, however, were produced using a process which involved pooling human blood plasma from up to 100,000 donors and concentrating it to extract the required factor. Blood products were known to transfer viruses such as hepatitis and this risk was vastly increased when they were pooled using the new techniques. This risk was further exacerbated when supplies of UK-produced factor concentrates were not sufficient to cope with NHS demand, and products were increasingly imported from the United States. In the US, high-risk paid donors were used, as well as using blood collected in prisons, increasing the risk of contamination with blood-borne viruses.

"These risks were ignored by leading clinicians and Government, who then failed to take appropriate action to end their use and return to safer products. Pharmaceutical companies and leading clinicians did not appropriately share, or even hid, information about risks from patients and patient groups. Many people were infected with deadly viruses during this time."⁽¹⁾

Rex was given contaminated blood products in the 1970s and 1980s and is now hepatitis C positive.

"That was the period when I was using vast amounts of Factor VIII because my right ankle was giving up. Each time you put it in, without knowing it, you were playing Russian roulette, of course. One... at least one, I think possibly two, but at least one haemophilic from Sheffield, his bullet came in the wrong place and he got... he got the lot."

LIFE WITH ON-DEMAND TREATMENT

Fortunately, Rex's liver is as robust as he is. It was some time, however, before he switched from on-demand

treatment to prophylaxis. On-demand was, after all, working well:

"When my wife was alive, we didn't do prophylaxis because it wasn't necessary. I could come out of the garage and say, 'I've just cracked my arm on the shed. I'd better get a treatment,' because I'd learned a bit more sense now. So, I'd wash my hands, Violet would get all the gear ready, I'd give myself a treatment, then I'd go back in the garage and finish what I was doing – draining the sump or what the devil I was underneath doing, but I'd just finish the job. And that was fine.

"I remember one horrendous Sunday when I couldn't... I'd got an arm that was getting quite bad and I wanted to go in there and I had seven attempts to get blood out of a vein. And I got seven plasters all over! Quite a session that was, but that was really a one-off. Oftentimes I'd miss, of course."

Being reliant on treatment meant that Rex and Violet always holidayed somewhere with ready access to clotting factor.

"...holiday-wise, we never went any further than Bournemouth, because there's a good centre. There's an excellent haemophilic centre at Bournemouth. Boscombe it is, actually, and the hotel is only about half a mile from there. We went there once a year, and very occasionally twice a year, for about 20 years.

"There was one particular time we got to Bournemouth – usually getting there about lunchtime – it comes to dinner time, we sit down to dinner, she draws the table leaf out and drops it that way and hits me across the shins with it. And, oh, hysterical she was. I said, 'No, you don't know how much...' I said, 'I must go.' She said, 'No, I'm sure you'll be alright.' I said, 'I'm sure I won't.' So it was straight to the phone, ring Boscombe, which I'd got the number. They said, 'Get down here. Get down here quick.' So, I had daily visits there for Factor VIII that week."

When Violet and Rex planned a shorter trip, they could take enough Factor VIII with them, provided they could persuade the hotel to help:



Image: In the 1970s, Rex played drums in local clubs around Doncaster with the Cliff Grey Big Band. "It was big, and a super sound – sometimes there were nine or ten of us"

"If we went anywhere else – Scarborough, for instance, we'd have an odd holiday in Scarborough – we would take Factor VIII with me, put it in a flask, put about three small jars in – by now, we're at about that sort of thing. You'd get three jars into a big flask and take it and ask them to put it in the fridge. And this hotel did. I said, 'Look, I'll screw it off and show you what it is. It's not fluid – it's just in case...' explanations. They accepted it, anyway, and it went into their fridge."

Rex has had his fair share of surgery over the years: both knees have been replaced twice and his teeth have been done. His first knee replacement lasted for 22 years (at a time when the expectation was 10–12 years).

"My drumming was all sitting. As I used to say, it's very low mileage. It's a very low mileage knee."

Which is not to say the procedures were straightforward.

"One in particular – this one – was done... I would estimate, possibly eight years ago. This was giving trouble because it was breaking, at the top here; it was breaking up and beginning to get loose, and you could do that with the ankle. So, he [the surgeon] had quite a job. It's a normal... oh, it takes no time at all; these guys do them in... I wouldn't say half an hour, but they're very quick with the knees. With this one, my wonderful surgeon took much

longer, but I'm sure he saved my leg. It was a special computerised one he'd had made, and it goes right down; it goes a hell of a long way down because of this break-up at the top there. Wonderful. Wonderful job."

PROPHYLAXIS – BUT MORE CHALLENGES

These days, Rex is on prophylaxis. A weekly dose lifted his Factor VIII level from 1% to 4%. But it has not been plain sailing. Violet had passed away and he'd been living at home on his own for four years. Then, two years ago, he suffered a severe nosebleed. It highlighted to everybody how vulnerable his situation was and precipitated a move into a care home, where he now lives.

"One way or another, talking to Sheffield [hospital] and talking to friends, they finally convinced me: 'If something nasty happens and you fell down or something nasty, what's going to happen to you? You're on your own.' 'Well,' I said, 'I've got my pendant.' 'Yes, but that's going to take time,' etc. They convinced me that this was a sensible thing to do and I came in."

This episode was a threat to his independence and mobility. Rex – a driving instructor with decades of experience behind the wheel – did not dare use his car for three weeks after the nosebleed.

A couple of weeks before our conversation, Rex had another severe nosebleed, this time in the care home. The staff are not qualified to assist with treatment, and although they know Rex has haemophilia, they don't know about its management.

"So, last week, when it started, it was really bad. I was... Well, to be honest, I was just getting up from the toilet – I was busy there, that's one hand occupied. I'd got a great mound of toilet paper in my left hand, holding my nose and trying to stand up and do the things I had to do. And at the side of me I pulled the cord, and luckily they were there pretty smartly – sometimes it's a long time, it depends what they're doing, you see. And to cut it short, one of the girls, one of the carers came, and I said, 'Hold my nose!' She says, 'I can't do that. I can't do that.' I said, 'Get in – I'm going to be dead if you don't stop this,' I said, 'Get some gloves, get some gloves on,' and she very sensibly went and put some gloves on and held my nose. And I'm yelling out, 'You'd better get...' I said, 'If we can get it stopped, I'll go and give myself a

transfusion out the cupboard.' So, I would have done it if we could just stop it. But it was pouring, it wasn't just... So, she held my nose until the ambulance arrived."

This nosebleed poses a threat of another kind:

"Now, because of this, I suggested that we go back now and do twice a week. So, now, twice a week will keep me at a permanent level of possibly about 7-8% of your level. And I'm hoping that that will... I'm frightened. That's a word I use not very often, because I've been there and done that sort of thing."

These severe bleeding episodes bring uncertainty and Rex now keeps a big towel by his bed:

"There's no means of knowing. You've not bashed your nose, you've not done anything, you've not picked your nose and done anything stupid. It just did it. Just did it."

"GO AHEAD AND DO IT"

Looking back on his many years of living with haemophilia, during a period when management has been transformed beyond all expectation, what would Rex say to a young person with haemophilia – someone who can look forward to a long life with much greater confidence than was conceivable in Rex's youth?

"I would say, in a word, subject to taking your factor, ignore it. That's it. Take your factor when you need it; do as you're told in that respect. Don't do what I did and think you'll be clever and it'll be alright on the night – it probably won't. If you're told that you need two shots a week, have two shots a week. Other than that, do whatever you're told to do and just go ahead with your life and just do it. And remember that you're going to have a bit of trouble here and there. It's not a magic carpet; you will have a few bits and bobs that don't quite run according to plan. Don't give it a thought. Just go ahead and do it anyway, and take your shots and take what comes."

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