

Rob Burrow MBE – Teams up with Trichair



The situation – Rob's background

Rob was born in West Yorkshire in 1982 and having made his rugby league debut for Leeds Rhinos in 2001 went on to become a legend of the game, making 493 appearances for his club, winning eight Super League titles, two Challenge Cups, three World Club trophies, and three League Leader's Shields.

Rob also made 22 appearances representing England, Great Britain and Yorkshire, and was inducted into the Leeds Rhinos' Hall of Fame in 2020.

The situation – Diagnosis

In 2019 Rob was diagnosed with motor neurone disease (MND) which is a degenerative neurological condition affecting the neurones in the brain and spinal cord, impacting on movement, body control, speech and all muscular control.

There are different types of MDN:

- Amyotrophic lateral sclerosis (the most common)
- Bulbar onset MND or Progressive bulbar palsy
- Progressive muscular atrophy
- Primary lateral sclerosis

Although each type has slightly different presentations, essentially, they produce the same or very similar symptoms.

Rob initially noticed some problems with his speech which led to investigations including an MRI and nerve conduction studies, the results of which were confirmed by a neurologist.

Over the last four years Rob's condition has progressed, and he is now reliant on support for all activities of daily living (ADLs).

The situation – Equipment

Despite Rob's initial reluctance to seek help, he had a visit from an Occupational Therapist who made recommendations for seating specifically.

Rob uses a profiling bed which he says has been a "real lifesaver" and it enables him to change his position regularly and remain comfortable.

Despite initially not making the decision to accept a specialist chair, instead opting for the comfort of his own domestic chair, Rob posted a Tweet (now X) stating he felt it was "time to consider a specialist chair".

This is when a mutual friend introduced Rob to Shaun McCluskey who works with Channel Healthcare and Tri-Chair.

Seating – Rob's goals

Shaun took time to get to know Rob and his family; recommending equipment should be the product of a relationship, a product of collaboration and an understanding of the person's goals. Too often these conversations are led by the sales representative or product expert, but for Shaun and Rob it was crucial that this process was clear, transparent and focused on what Rob and his family wanted to achieve, whilst providing information that empowered them to make an informed, capacitated decision.

Rob was able to clearly identify his goals for seating, highlighted in his own words:

"...to be able to sit comfortably for prolonged periods of time and to ensure that I don't develop pressure areas/sores. I have drinks and eat my meals in the chair, so I need to have

adequate head and trunk support for feeding...It is essential that I have good sitting posture for everyday tasks such as eating and drinking. I use a communication device, so I need to have good posture to be able to use my machine to communicate using my eye movement."

Rob's goals therefore were:

1. Maximise comfort.
2. Reduce risks of pressure damage.
3. Support good posture for everyday tasks and communication.
4. Suitable head and trunk support for eating and drinking.

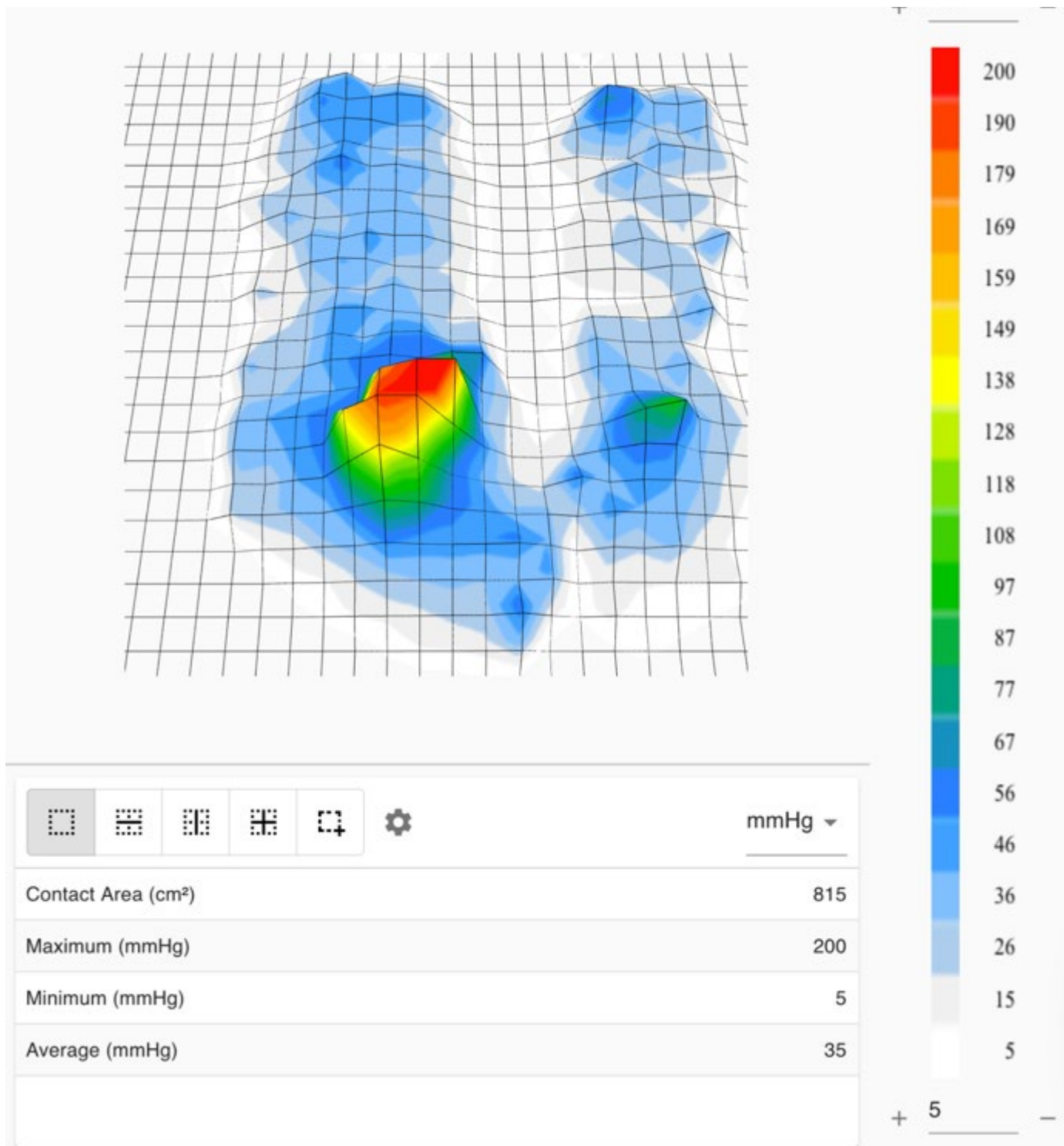
Rob also made it clear that he and his wife wanted to avoid turning the house into a healthcare setting, and equipment needed to be aesthetically pleasing as well as unintrusive.

Challenges and Risks

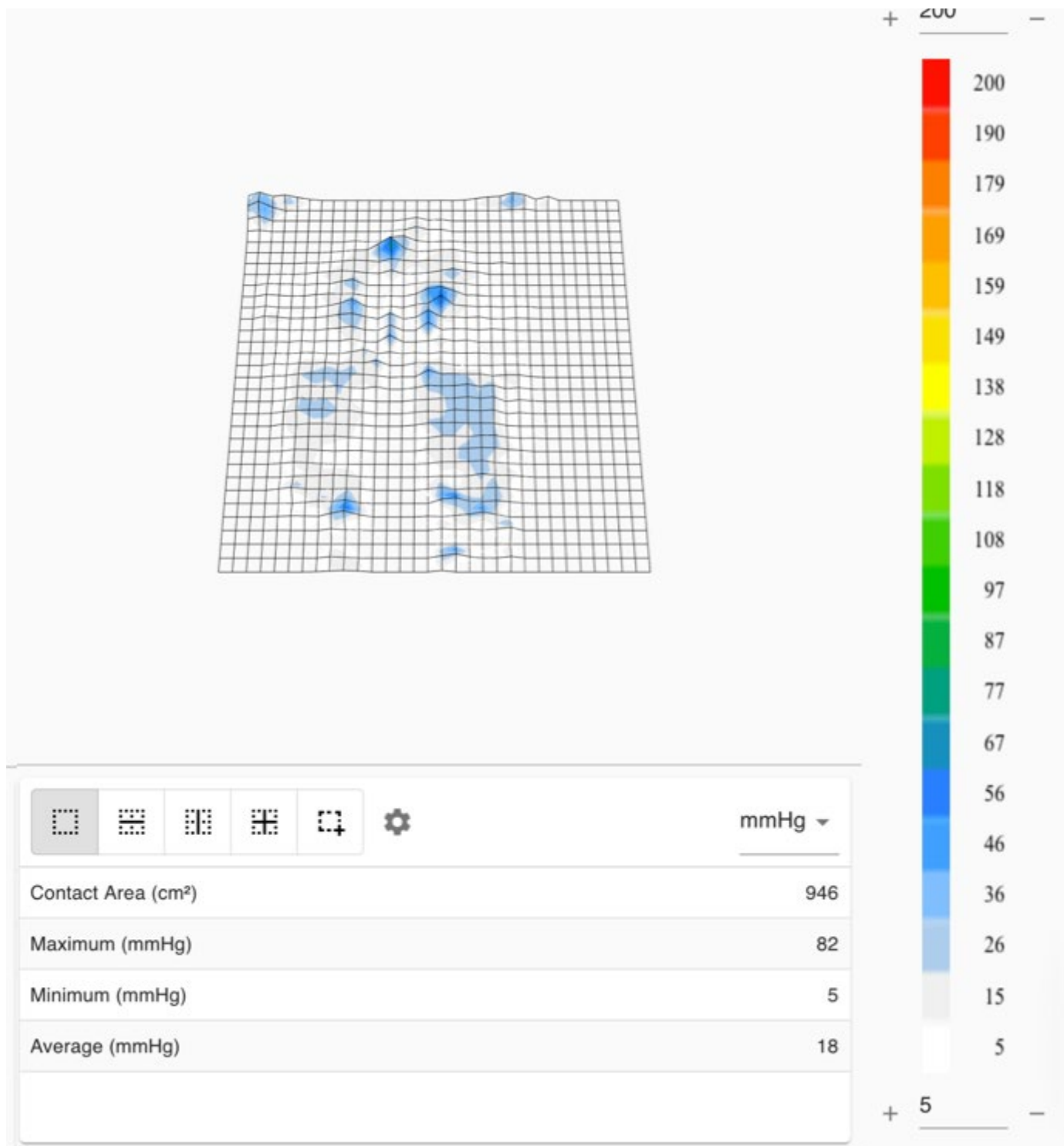
Fatigue: Rob becomes tired quickly and this impacts on both posture and his ability to engage in activities that are meaningful to him, particularly with his family.

Pressure: The chair that Rob was sitting on initially not only provided no pressure relief but was actively generating heat and encouraging sheer. Due to Rob's reduced core strength and balance he was leaning to his left side, with pressure mapping conducted to provide key evidence which would support Shaun's recommendations and Rob's decisions. Shaun made contact with Andy Robinson, of Apollo Healthcare Technologies, who carried out extensive pressure mapping.

The pressure mapping identified some key areas of risk, including the left buttock, ischial tuberosity and right thigh due to windswept posture.



Initial Map Taken.



Final Map with amends made to seat.

Posture: Rob's sitting posture, particularly relating to trunk and head support, was compromising a safe swallow and therefore increasing chances of aspiration.

Occupational deprivation: Each of the above challenges impacted on Rob's ability to engage in meaningful activities and activities of daily living. His roles were being even more greatly affected and this was impacting on carers around him.

Recommended solution

Through a combination of time spent with Rob and his family, listening carefully to his views and goals, and providing evidence to support the rationale, Shaun recommended the Tri-Chair Three which is a tilt in space, adjustable seating system which, as it's modular, can be adapted to meet Rob's changing needs.

The Tri-Chair team also recommended a moulded seat and backrest which provides even more support when Rob gets particularly tired. As well as supporting Rob's goals, this option allows Rob, his wife, and care team, to interchange cushions depending on the social situation and environment, in order, to reduce the healthcare look and feel of the chair whenever that is appropriate for them. Another example of true collaboration.

The outcome

Rob had a trial of the Tri-Chair Three, supported by Shaun and the team so that it could be altered to meet Rob's specific needs. This included a pommel to prevent further adduction and the moulded seat so that pressure was redistributed more evenly without Rob having to be in a tilted position so regularly. This in turn meant that Rob could be more engaged and communicate with good eye contact, promoting dignity and respect.

The outcome was the product of a truly collaborative process, built on trust. This trust was earned through active listening, in order, to understand and not simply to provide a response. Simply asking closed questions such as "are you comfortable" to someone, particularly a person with communication difficulties like Rob, will never lead to the 'gold standard' outcome; it cannot be client centred and will not ensure that the recommendation meets broader goals.

What did Rob say?

"...the design of the chair means that it can be adapted to meet my needs, for example, I felt that the trunk support was too restrictive on one of my chairs, so the pads were removed without compromising my overall comfort or posture in the chair. Extra padding/support can be added, and the chairs can be tilted with feet up/down which helps alleviate pressure. The Tri-chair has improved my quality of life.

I don't think I would cope without the chair which was tailor made for me. I certainly miss my tri chair when I get away somewhere. I have to look forward to the time I have my home comforts."

Rob is a sporting legend, an activist, a hero; but he's also a son, a husband, and a father. Rob never asked for 'special treatment' and he didn't get it. Everything that Rob received from Shaun and the team is provided to every client they are lucky enough to meet, because they are all someone's child, someone's parent, someone who is loved, and they all deserve the best.