

This is a story of how a process orientation can effect results and outcomes, and the shift in orientation that made the final difference...



Brian lived with his wife Anne. Brian was terminally ill. It was his wish to stay in his own home for the rest of his life. His wife Anne supports this wish and supported him at home.

Anne reported to the national Be Human Register in October 2020....

At this moment of time during the COVID pandemic we are minimising the risk of healthcare workers coming into our home and spreading the virus. Brian has kidney failure. He has a Nephrostomy in his left kidney with a drainage bag. This tube is basically keeping him alive.

In his abdomen he has a very large tumour bigger than a full term baby. The tumour is solid and is putting pressure on his hips and nerves. His legs have Lymphoedema which are heavy with water. His mobility is very poor. His right leg is paralysed due to surgery. His femoral nerve was cut.

He has anemia which makes him feel very tired. He has secondary lung cancer... sleeping slightly raised makes him more comfortable. A lateral tilt bed will make life easier for me to manage my husband. Having a lateral tilt bed with an appropriate mattress would make such a difference to mine and Brian's life. I would be able to change Brian's Nephrostomy much more easier as I would be able to tilt the bed in a comfortable safe position. I would be able to apply cream on his sacral pressure areas. And creams to his legs. The constant turning mattress would give him the comfort he needs for a good nights sleep as weight would be distributed. It would make a difference on my back as well as I have Osteoarthritis in knee and hip. It would also mean I would not have to get up in the night and reposition him. Allowing me to sleep as well. When getting out of bed the bed would tilt allowing him to position his legs without bending.

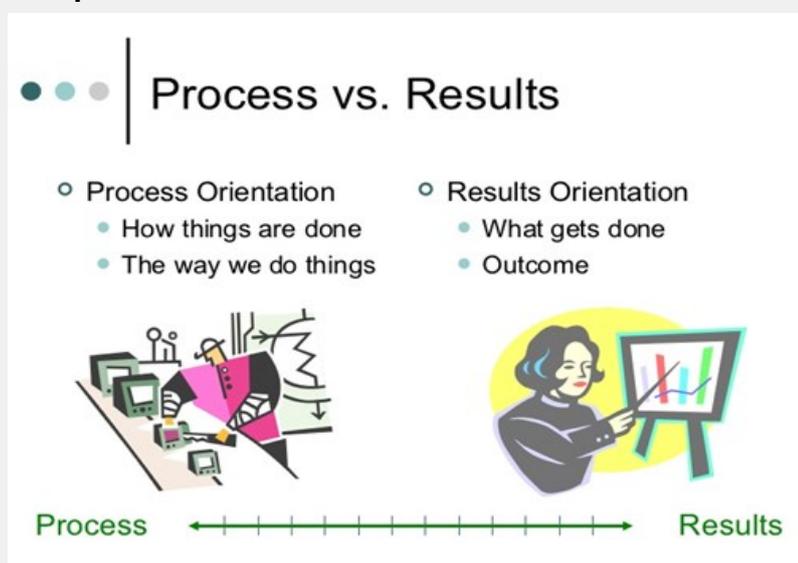
Anne had requested this equipment and her GP and district nurse agreed that having a lateral tilt bed was both needed for Brian and would be beneficial for Anne as she continued to care and support him in the home. Anne reported that direct healthcare professionals all agreed but as the paperwork request for the bed went through the approval panel process the clinical need and requirement for a lateral tilt bed was not identified on the paperwork therefore the request was declined. The request for the bed was submitted on 5 occasions and was declined each time as the paperwork did not specify that a lateral tilt bed was required for Brian.

I picked up the report as part of the Be Human support and talked to Anne. I started to contact City Health Care Partnership CIC to find out what the situation was and why the requests for the bed were being rejected. The process of getting in contact with anyone was tricky, leaving numerous messages and voicemails before the very helpful CCG Patient Relations Team picked it up and started to help to escalate the issue to find out what had happened. By the 2nd November a new prescription for the bed was done.

However, Brian was assessed for a bariatric bed, when the bed was delivered it became clear that the bed wouldn't work for Anne and Brian as it was a foot wider.. Its hard to describe the various to and fro conversations and the time and energy it takes, but by this latter stage Anne & Brian had had enough. They already had found the bed they needed but the system doesn't work like that, the system needs to process through from assessment to prescription and then if the prescribed bed was not available in stock a further level of clinical reasoning and justification must be submitted. In this situation the justification was not sufficient to "allow" the system to get to the next stage in the process. I have to say everyone I spoke to knew the dilemma, sympathised and empathised but couldn't see a way around this process as it was "the way things were done". Anne ordered the bed they needed and asked that be on trial whilst the process issue took place. The trial could not go ahead due to covid.

By the end of November (6 months on from the initial requests) Brian had the right bed at a cost of using their own life savings to gain it. Whilst happy he had the bed he needed, surely this cannot be right? No one agreed it was right. Brian was fast tracked through the CHC process and as part of CHC assessment process it was agreed that the cost of the bed would be reimbursed..

For me watching and supporting this I could see two conflicting dimensions in place, one was orientation on process and the other an orientation on the outcome.



These were also conflicting for individual clinicians and administrators. I noted nearly everyone I spoke to about this dilemma was lovely! They understood it at a human level but were conflicted themselves by the “due process”. Obviously for Anne & Brian their only interest was the outcome for Brian and the due process led to too much energy being focused on a fight instead of the energy being preciously preserved for each other.

The Be Human RACA (register, advice, conciliation, arbitration) works to try to get some power to people’s elbow, not just those who receive health and social care but also those working in some of the difficult systems of health and social care.

“With added pressures on families, alongside reductions in support from public services in recent years, we believe it is everyone’s responsibility to look out for each other and help where we can. We have therefore established a movement to positively encourage a better approach and foster flexible and supportive attitudes in all organisations – public, private, commercial and voluntary. We fundamentally believe people would rather help than hinder others but that often complex fragmented systems can get in the way of this” Building personal power, key findings from the Be Human Register Feb 2021 www.be-human.org.uk

The people, like Anne & Brian, who have asked for assistance linked to the issues registered needed this to be provided in a range of ways linked to the issue and their local and personal context. The forms of assistance can be categorised as:



Many families left to situations such as this move fairly swiftly from 1 to 6..missing out the other options of support, (3,4 & 5) that can prevent further breakdown in relations by going through a litigation route.

In each of these situations, operating at different levels of interventions there were some common experiences and lessons:

- ⚙️ Gain a better understanding of wider context leading to “win-win” results - identifying blocks in the system that are not in patients/ persons best interests or that of the professionals or system.
- ⚙️ The vital importance of seeing the person as a whole and in their context.
- ⚙️ The need to then achieve a whole system response rather than be limited to responses from single elements and processes.

The CCG stated

"Staff across the NHS care passionately and work really hard to provide everyone with person-centred care that best meets their individual clinical circumstances, ensuring that the individual and their family remain at the heart of everything we do. We recognise NHS processes sometimes mean that decisions take longer than we would like but we all do our best to keep patients safe and I am so glad we managed to successfully resolve this for Brian."

Anne and Brian reflected

"Why are there are so many levels that a referral has to pass through? District nurses, Occupational therapists and GPs are on the front line and know what equipment is needed. Others in the system just see pieces of paper or a computer screen and make judgment on the information given rather than see the individual. A lot of money could be saved by eliminating some of this process. Our message to others is lets all fight for what we believe in ...We are all individuals with individual needs and don't fit the same box" BE HUMAN

Brian passed away on Saturday 10th April at home with his family at his side.

Anne stated "He fought a long battle over 15 years and had life changing surgery along the way. He always had a smile on his face, he was never bitter and took it all in his stride. The last two weeks have been challenging but we did get wonderful care".

In Memory of Brian Luke (Anne's Rock)

www.Be-Human.org.uk

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