

# Case Study 1

## Les

### ***Learning Disabilities Transforming Care Patient Journey Experience***

Les consented to sharing his hospital discharge story and has specified that he wants you to know who he is and not be anonymised. He feels it is important that his experience is recognised, understood and that people know about and learn from his experience.

Les is foremost a Sunderland supporter as well as a jovial and witty gentleman whose company you will leave with a smile because of the type of character he is and how he is such a considerate gentleman.

Les has a diagnosis of a Mild Learning Disability, an Emotionally Unstable Personality Disorder and Type 1 Diabetes. Les has spent his whole adult life, 36 years, in either prison, long term hospital (including 10 years in high secure services), residential care and supported living. Les is now 54 years of age and feels he is ready to share his experience of long-term care services to try and influence change with the system and prevent what happened to him happening to others.

Durham County Council (DCC) commissioning team started working with Les and his wider care team in late 2020, to identify a discharge plan following his recall to hospital in May 2018, under Section 37/41 of the Mental Health Act 1983.

Les described his overriding feelings when detained in hospital as 'frustration, no hope, lost and angry with tribunal after tribunal', Les stated that being detained in hospital was much more difficult than his experiences in prison, 'In prison you know when you are coming out, in hospital you have no idea and no hope'.

Les reflected upon and recognised what factors made him feel frustrated and angry. Primarily, the lack of control he had over his own life and decision-making when in hospital, prison and other care settings. Les expressed if someone was sent to prison they knew when they were getting out in hospital he didn't know!

Les recalled how scared he felt in the high secure hospital, he had two episodes of detention there, each one lasting 5 years. He recognises his poor coping strategies at that time and his actions were serious but didn't feel he had a way out. Les openly speaks about him experiencing trauma during these periods of detention - Les tells us he saw a person killed, and at another institution staff scratched a picture of his father with a key to deliberately torment him (this is now being digitally restored for him, with Kate O'Brien ICB LD & Autism Lead, organising payment for this after he recounted his story to her during a visit to his new home.) Les highlighted from his hospital experience "you have people winding you up every day" and the restrictions on the wards caused him anxiety, with him being restrained and secluded because 'I was so frustrated and had so many worries and kept getting angry'

Les has completed treatment programmes while in hospital which have enabled him to utilise and employ appropriate coping strategies in times of stress, anxiety and agitation. As a result, he is now confident in his own ability to cope with the stresses of daily life and regulate his emotional response to these as he now has control over his life. He is proactive in using his coping strategies; going for a walk/cycle and having time alone to think things through with more clarity.

Les commenced his transition into the community with a conditional discharge from hospital on the 23<sup>rd</sup> June 2022 and he has gone from strength to strength building a life in his local area with his family, friends and neighbours.

The commissioning team initially started talking about Les's discharge in late 2020. Les was an integral contributor to the planning of his own future accommodation. Stakeholders involved in his holistic care needs were; care coordinator, ward staff, Secure Outreach & Transitions team (SOT) and commissioning, initially exploring with Les what his thoughts were about discharge and what he felt he would need to ensure he had a successful discharge into the community. Les was clear in his views; having his own home in the community with consistent support everyday visiting him would work.

At this point some professionals were extremely doubtful about Les's ability to live independently in the community. However, this was something we continued to pursue as it was clear previous options had been tried and failed for Les and this was what Les was saying he wanted and would work. The MDT agreed that this was the best option for a successful discharge and each service worked in collaboration and with Les to achieve his vision and reality for life in the community.

DCC's Support and Recovery team were recruited to the process as it was established they were able to provide the support Les required.

Discharge planning meetings were held weekly, with Les and the whole MDT in attendance. During the discharge planning and transition we consistently ensured all decision making was focused on Les's views and his aspirations.

With assistance from the Support and Recovery Team and ward staff Les was able to apply for housing via Durham Key Options. Les was successful in getting a 2-bedroom house complete with a large garden overlooking the Durham countryside and close to his family.

The whole team from Les, the SOT team, Ward Team, Care Coordination, Commissioning and Support and Recovery Team worked together to ensure that Les's discharge plan was successful, from risk assessments to ensuring Les got the wallpaper he wanted (though comments were made around how Les has expensive tastes)

Once Les had found the house, he was happy with, DCC commissioning used the Community Discharge Grant monies to pay for the staff team supporting Les during the transition period from hospital; to furnish his house and pay the rent until he was discharged fully and Les was able to claim Housing Benefit.

The transition period from hospital to his two-bedroom house was approximately 6 months, staggered Section 17 leave was authorised by the Ministry of Justice, initially starting with visits during the day enabling Les to get his home ready for him to live in and taking deliveries with support staff and family to help. Once the house was ready for occupancy Les started overnight stays, initially starting with one night.

Les reflected on his first night in his own home, he describes it 'being scary', the house was so quiet in comparison to the hospital and as he was lying in his own bed, he was expecting noise and the light of a torch being shone on him through the door as this was what he was used to with the regular observation checks in hospital. He has described how nervous he was in his own house by himself without anyone there and how different it was but how he gained the confidence and now loves sleeping in his own bed at night in his own home.

Les worked up to 5 nights a week staying in his new home, until the Ministry of Justice authorised his conditional discharge on 23<sup>rd</sup> June.

Les initially came out of hospital with 2:1 support 4hrs a day, 7 days a week, this has now been reduced to 3 hours a day 5 days a week. Les and the support team around him anticipate this will continue to reduce over time while increasing his independence.

Les described how he took one step at a time and says how the team around him supported him to achieve what he wanted for his life and future. Les continues to thank staff who supported him and recognises this support, alongside knowing how the team's confidence in him, enabled him to have the confidence in his own ability to live independently in the community.

Les has been living in his own home for over 7 months and says he loves it. Les knows he has his independence and choice in respect of what he wants, and the support staff who visit him are there only to support not choose for him.

### **Les's future**

Les has just been re-assessed in respect to his capacity to manage his own finances and has been deemed to have capacity. He is excited that he is opening his own bank account and will be able to manage his own money without having to make a request to someone if he wants/needs extra money to make a purchase. Les knows he has support around him to set up his direct debits and budget planning.

Les also has plans to go on holiday and is already booked to go to Flamingo Land with his family. He is starting Shaw Trust day service (he likes gardening) where he feels he will not only be able to work independently when given a task but will be able to offer support and work alongside others who may not be as able as he is. He is also planning on redecorating his house in the new year, a house he loves and takes pride in.

Les attends a football group every Wednesday and is part of the football team taking part in local tournaments. Les is very artistic and has a room in his house to do his art and crafts. Les also has a bike which he has bought himself to get around independently as well as a means to maintaining good physical health. He is planning to undertake a bike ride for charity.

Les is also starting to share his story further and was invited to speak with Amanda Pritchard, NHS Chief Executive (unfortunately this was cancelled) Les is also starting to explore options with Inclusion North and the potential to share his story with other patients.

Les describes his life now using the following words; 'no pressure, excited, no one telling me what to do, relaxed, having a perfectly good time in life'

Helping others is very important to Les whether it is raising money for charity or sharing his story, he wants to help change the system and give others in hospital hope and inspiration that they too can also have a life like his in the future.

### **Les at Christmas in his house and on his bike**





Les's garden and some of his art work



