

## Spotlight – case study: Mr X

Mr X was diagnosed with COPD ten years ago and has managed his condition with medication for the ten years of being diagnosed. Before this he was quite active and enjoyed life and had many hobbies. But on the 2<sup>nd</sup> of February 2021 he was taken into hospital with swollen ankles and breathlessness. Whilst there he caught Covid 19. Fortunately he had his first vaccination and got mild symptoms. As the hospital started to investigate Mr X they found that he had heart failure and a hole in his heart. Consultants had many discussions about how to treat Mr X; they concluded that it would be too much of a risk to operate on Mr X. He was diagnosed with decompensated heart failure with reduced EF, cor pulmonale LRTI, pulmonary hypertension + advanced COPD, left leg cellulitis, Covid positive. He was hospitalised for 8 weeks and was put on oxygen. He was released from hospital and an oxygen concentrator was installed in his home; he was on 4 litres of oxygen. Mr X was admitted to hospital on numerous occasions with illness due to his previous diagnosis; this was a regular occurrence throughout the year. He couldn't leave the house at first because as he was reliant on receiving oxygen. After some time, after he had asked on numerous occasions if he could have portable oxygen tanks so he could at least leave the house, the NHS provided him this through BOC [oxygen provider]. He has support from the heart failure nurse and lung nurse weekly to check his condition and monitor him.

In October 2021 he was admitted again with an infection which was pneumonia and was there for many weeks but again he recovered. He was now on 8 litres of oxygen at home and was in recovery from his illness.

Throughout Mr X' admission to hospital he had numerous CT and MRI scans to identify what was going on inside his body.

On 24<sup>th</sup> February 2022 Mr X was admitted to hospital again with shortness of breath and swollen legs as he was retaining fluid. This was a regular occurrence with his condition. He had CT scans yet again and the results shown was a lung nodule that was likely to be cancer. As it had grown it was decided that due to frailty, he would not be suitable for any intervention, the best approach would be supportive care.

Whilst in hospital this time the consultant asked Mr X why he was on rivaroxaban, an anti-clot agent. He replied that on his first admission 2/02/21 to 19/03/21 that the doctor put him on them due to a blood clot. They reviewed the discharge letters, the letters states DOAC (direct-acting oral anticoagulants) was started during that admission. Another letter stated he had a PE. We have looked through the discharge letter it states no PE. They looked through the results of all CTPA results and no PE was seen. Mr X had had covid during that period; in view of this they stopped the DOAC.

Mr X was sent home he is currently still on 8 litres of oxygen but whilst in hospital he was on 15 litres then weaned down to 8 litres.

Mr X has the lung and heart failure nurse visit him alternative weeks; this is the only support Mr X gets. He was referred to LOROS. He had one session to talk about his last wishes. Mr X indicated that this was a lot to take in and wanted more support like counselling one to one. This was 8 months ago and still no support, so Mr X has to deal with all these changes with only his partner to support him. This has proved difficult for both of them as his partner is his primary carer and well as the closest person to him.

Mr X feels that he has been abandoned and sent home to die. His quality of life is so very limited now his mobility is very restricted due to breathlessness and other health issues. It is hard for him to speak to his partner because he doesn't want her to get upset and feels he needs to talk to someone non-related.

Now this section is how it has affected his partner Miss Y.

Obviously, the shock of Mr X's health deterioration has been hard to handle as before this they had a reasonably active life together. Miss Y feels that an assessment should have been carried out before he left the hospital the first time as she didn't know what to expect and didn't know how mobile Mr X would be. Nothing was done, so she had to predict what his needs would be so an adjustable bed was purchased and a commode as she predicted he would be able to get up the stairs. She was right, he couldn't. As Mr X's health has been deteriorating his needs have increased, so adaptations have been installed in the home bought by themselves, and a downstairs toilet and washroom has been installed paid for by themselves. It was only after all this was purchased that they were asked if adaptations were needed at this point; they said no as all adaptations had been purchased.

Also affecting them is the fact that the oxygen machine has made the energy bills in electric double, but it is needed so we have no choice. No help available for this. Miss Y works and can get no financial support.

Miss Y feels let down by everyone at this point. She feels deeply that Mr X is not supported in the way he should be and not knowing how much time they have together as Mr X will worsen and die. In August 2021 Mr X was told by doctors that he would be lucky if he seen his next birthday which is August. We have had to break the news to our grown-up children and Miss Y has been supporting them as well as it's been a very emotional journey.

What should have been done in Miss Y's eyes.

1. Mr X should have been assessed before he left the hospital the first time in February 2021 to see what adaptations and equipment, he would need to make his life easier especially with mobility issues.
2. He should have been offered counselling much sooner as it's a lot to take in especially when your life is going to be cut short and you have limited time left.
3. Consultants must make it much more understandable about diagnosis as patients don't always take on what they have been told and patients' partners

and relative closest should be spoken to about diagnosis and what to expect in the future.

4. Patients that are terminally ill should get better access to their GP and the GP should also be monitoring the patient's health which does not happen currently.
5. Carers of terminally ill relatives should get more support especially if they are the primary carers as their loved ones illness affects their own mental health and wellbeing.
6. Carers and patients to be made aware of what support they can get from different agencies and local government.

Final note from Miss Y:

I feel that each patient has different needs and that if you don't meet the criteria of the support on offer you don't get the support you need. Everyone is different and everyone's needs are different. if we don't start treating everyone's needs as different there will be vulnerable people who miss out on vital support they need.

Examples are

- Some people don't know that if you're a homeowner you can put in for adaptations grant from your local authority.
- If you are working and earn £19,000 plus you get little or no financial support with rising energy cost, mortgages and other household bill the amount above doesn't stretch far. It seems we have the working poor being more affected.
- Support information is not readily available to people.

In conclusion I praise the NHS services for what they provide but I feel more can be done as far as support after a patient leaves hospital from GP services, counselling services etc.

I would just like to say at this point that the NHS, ambulance services and community heart and lung nurses have been a lifeline for Mr X.