


Board of Directors' Meeting 11 August 2022

Agenda item	143/22			
Report Title	Patient Story – Living with Idiopathic Pulmonary Fibrosis			
Executive Lead	Director of Nursing			
Report Author	Lead for Patient Experience			
	Link to strategic goal:		Link to CQC domain:	
	Our patients and community	√	Safe	√
	Our people	√	Effective	√
	Our service delivery	√	Caring	√
	Our governance		Responsive	√
	Our partners	√	Well Led	√
	Report recommendations:		Link to BAF / risk:	
	For assurance		BAF1, BAF2,	
	For decision / approval		Link to risk register:	
	For review / discussion			
	For noting	√		
	For information			
	For consent			
Presented to:				
Executive summary:	<p>The storytellers describe an emergency admission to the Trust in May 2022. Once stabilised in Resus, the storyteller was transferred to the Respiratory Ward and subsequently ITU as the level of care he required increased.</p> <p>The Board are invited to watch the film in which the storytellers use their own words to describe the events, how, when times were challenging, the support they received from staff had a significant impact upon their experience and memories of this challenging time.</p>			
Appendices	Digital Story: Living with Idiopathic Pulmonary Fibrosis			
Executive Lead				

1.0 Introduction

1.1 This story captures a patient and his wife describing his recent experience during an emergency admission to the Trust in May 2022.

2.0 Background

2.1 The storyteller describes how he was diagnosed with Idiopathic Pulmonary Fibrosis in 2016, a debilitating disease which causes irreversible lung damage. Initially he managed to maintain his usual level of activities, maintaining a career he enjoyed and active involvement in martial arts classes.

2.2 In 2019, at the age of 48, maintaining usual activities had become increasingly difficult, culminating in termination of his job due to the level of physical activity involved. The storyteller started to struggle and became increasingly reliant upon oxygen therapy. In 2020 a double lung transplant was identified as the next level of treatment and he was placed on the waiting list.

2.3 In May 2022 a respiratory infection resulted in an emergency admission and treatment in the Emergency Department, the Respiratory Ward and subsequent transfer to ITU. The storyteller outlines how frightening it felt to experience such difficulty in breathing, and whilst his wife, nurses and doctors were there, he felt lonely and afraid.

2.4 Throughout the time in hospital, he shares how he felt recognised as an individual, rather than being seen as just a number. They both felt support from the teams looking after them, as though they were standing alongside them fighting the difficulties with them.

2.5 Whilst in ITU, the storyteller asked to see a Chaplain as he wanted to be baptised, as he wanted to make peace with God at what he felt could have been the end of his life. The baptism was facilitated at the time of request and the storyteller shares how this offered a sense of relief and calmness.

2.6 The storyteller also highlighted that he would like to be married to his partner, something that was facilitated by the ITU, Palliative Care and Chaplaincy Teams. The storytellers explain how staff went out of their way to support them in achieving his ambition to be married.

2.7 The storytellers explain how all patients were made to feel special, and could not do enough to support them, going over and above what is expected of them

3.0 Risks and Actions

3.1 Following the patient story being captured the subsequent actions have been taken:

- The digital story will be shared in a range of areas across the Trust to raise awareness.
- Longer versions of the patient story have been captured to share with the Chaplaincy Team, Respiratory Team and ITU Team involved in his care and treatment.

4.0 Conclusion

4.1 The Board is asked to note the patient story and take assurance of the work being undertaken to listen to and be responsive to feedback from people accessing services within the Trust to improve patient experience. Learning from feedback and using patient experiences to drive improvements.