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## WS20 – Complex psychosocial/nursing case studies

### WS20.01

**Empowering self-management using intensive support in a patient with challenging Cystic Fibrosis-Related Diabetes and renal failure**

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**Background:** This case describes the complexities facing a 27-year-old woman with challenging Cystic Fibrosis-Related Diabetes (CFRD). Her genotype is F508del/G551D and she started ivacaftor in 2013, Baseline $FEV_1$ was 70%-predicted and co-morbidities included pancreatic insufficiency and chronic *Pseudomonas aeruginosa* infection. CFRD was diagnosed at the age of 14 years. Prior to starting ivacaftor, she was underweight but has since maintained a healthy BMI >22 $kg/m^2$. In 2016, she became pregnant. Ivacaftor was initially stopped but then restarted due to a drop in lung function. She developed severe pre-eclampsia and delivered a healthy baby by emergency caesarean at 30/40 gestation.

Her CFRD control declined following pregnancy and flash glucose monitoring (FreeStyle Libre®) was started in May 2019 when her HbA1c was 79 mmol/mol. After 3 months, her insulin regime was amended to a more gradual release basal insulin and a faster acting mealtime insulin, and her HbA1c improved to 60 mmol/mol. Further challenges arose in July 2018 when her previously normal renal function declined to an eGFR of 65 ml/min. A renal biopsy confirmed diabetic nephropathy and she was started on peritoneal dialysis in June 2020. This treatment represented an additional burden, impacted her engagement with CF treatments and worsened her glycaemic control.

In November 2020, her $FEV_1$ deteriorated to around 30%-predicted and she developed a severe pulmonary exacerbation that required intubation and mechanical ventilation on ICU. She survived this episode but her $FEV_1$ failed to improve. She switched to Kaftrio in June 2021. Her CFRD control remained challenging with an HbA1c of 99 mmol/mol, and she was started on an Omnipod Dash insulin pump. She managed this well and benefited from constant basal insulin delivery with improved ability to provide effective insulin boluses.

Weekly phone calls and regular home visits from the dietitian, specialist nurse and physiotherapist were required to review her treatments, support her mental health, and help her prioritise her increasingly complex care. She was listed for renal transplantation in October 2021 and received a deceased donor kidney in December 2021. Her kidney function has normalised, she is less fatigued and her $FEV_1$ has improved to 55%-predicted.

**Discussion:** This case highlights how individualised treatment and intensive support can promote self-efficacy to positively impact adherence and outcomes. An enhanced collaborative approach aiming to improve patient engagement and treatment has led to a significant improvement in glucose control. The burden of glucose monitoring and insulin delivery has reduced despite the additional challenges of peritoneal dialysis. The patient reports feeling more in control of her diabetes since using these devices, especially during her peritoneal dialysis treatment. Close liaison between the CF and nephrology teams was essential to ensure safe and effective care.

**Conclusion and Learning Points:**

Intensive multi-disciplinary support helped empower this patient to manage her extremely complex medical care.

Flash glucose monitoring and insulin pump therapy can be a very helpful tool to improve self-efficacy in managing CFRD.

Peritoneal dialysis places an additional treatment burden that can significantly impact other CF treatments.

CF continues to present a considerable challenge despite highly effective CFTR modulator therapy.

### WS20.02

**Input supporting a young person with increased cough suppression in the context of COVID-19**

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**Background:** Young people with cystic fibrosis (CF) can experience a cough, chronically and/or during infective exacerbations. Cough is an effective method of clearing secretions from the larger airway (Belli et al., 2021) and it has been shown that having an ineffective cough can cause retained secretions and chronic inflammation, among other symptoms (McIlwaine et al., 2017). Cough is also one of the three main symptoms of COVID-19. As a result, over the past two years, there has been an increased awareness in the general population of cough in other people.

M, now a 10 year-old girl, was diagnosed with CF through newborn screening. Throughout her early life, she had regular hospital admissions for IV antibiotics treating infectious exacerbations. At the point of exacerbation, she had always experienced significantly productive cough which impacted on day-to-day functioning. M is a confident young lady who had previously presented as having a good understanding of her diagnosis and symptoms and the reasons for engaging in treatments. She had been very open with peers about her diagnosis and how this impacted her, including presenting to her class to help them understand her CF experience.

In the summer of 2021, M had an admission for a routine bronchoscopy, and following this, became acutely unwell with an infectious exacerbation requiring an unplanned two-week admission for IV antibiotics and intensive physiotherapy. It became apparent while engaging in physiotherapy sessions during the admission that M was cough suppressing, which was atypical behaviour for M. To explore this further, a referral was made to psychology.

During an initial assessment, M shared that she had recently had experiences of others commenting on her cough and moving away from her in public. She also reported negative reactions from younger children in school. M reported that this had left her feeling that cough was a bad thing and in turn had been engaging in cough suppression when in school and out in public. She was also avoiding social situations with strangers to reduce the possibility of her experiencing negative feedback about her cough.

**Discussion:** It was considered that cough suppression may have been a contributory factor to M's exacerbation. Input supported M in exploring her understanding of others' reactions to her cough in the context of the pandemic. It allowed her to recognise her engagement with avoidance and why this had developed.

Time was spent with M helping her formulate and understand the responses of others. Input focused on externalising the difficulties and understanding different perspectives, alongside helping M to develop helpful responses which left her feeling more empowered and less fearful. M recognised that not all those in school had an understanding of her diagnosis. In response she prepared a presentation to share in a school to help younger children's understanding and reduce fear around her symptoms.

**Conclusions:** Recognising and understanding reasons for M's cough suppression allowed for support to be offered to allow her to change behaviours with a positive impact on physical and mental well-being.

Following on from M's case, routine screening for cough suppression has been integrated into assessment. This has highlighted that a large number of patients are having similar experiences as a result of the pandemic and has allowed for physio and psychology input to support with worries and fears.

### WS20.03

**What to hope for when there is no hope**

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**Background:** Cystic fibrosis (CF) afflicts 75,000 people globally. The arrival of the new CFTR (cystic fibrosis transmembrane conductance regulator) modifying medications provide hope for potentially 85–90% of CF patients. This will rapidly change the future outlook for many CF patients, with new and positive opportunities. However, where is the outlook for those patients who are not eligible for CFTR modulators. What of those patients who have end-stage disease awaiting lung transplantation. This presentation discusses the different understanding of the concept of hope and how it may be used to help patients when the horizons look bleak.