Caring for the Carers

Background
There are over 17,000 people in Lothian living with COPD (Chronic Obstructive Pulmonary Disease) and possibly even more family members living with the impact of the condition.

The Lothian Pulmonary Rehab Programme, established in 2014, involves a tailored exercise programme and education sessions for people who have COPD. If their family understands the value and impact of this treatment, then the person may be better supported to successfully self manage. Looking after the care giver’s own health needs may sustain their ability to continue caring.

Chronic obstructive pulmonary disease is a major health problem in the UK resulting in significant burden for patients, families and the health service. Early discharge for exacerbations and providing hospital-at-home care prevents or reduces re-hospitalisations. Unpaid family carers are crucial to the success of these interventions. Understanding carers’ needs is important if health care professionals are to support carers in their care giving role.

Aim
The aim was to provide disease information, to help maintain family relationships and to address the health and wellbeing of the carers themselves.

Carers perform a variety of complex and challenging tasks and are essential partners in the delivery of health care services. Most have little training and can suffer from chronic stress. Understanding about COPD and how to assist their loved ones can support the carer and preserve the person’s function. Carers are welcome to attend Pulmonary Rehab appointments but they often use this time to catch up. There may be advantages in bringing a discrete group of carers together to one strategic session, where they could learn about COPD and discuss common issues in a safe and open environment. Armed with greater knowledge and equipped with practical tips, it was hoped that the carers would be more confident in their role.

Method
Staff from East Lothian Pulmonary Rehab and Carers of East Lothian, delivered a support and information afternoon in October 2016 for 10 carers of people with COPD. The next course was run over two sessions to include more information and more time for problem solving and reflection.

The event was repeated in October 2017 with 15 carers attending two afternoon sessions in Musselburgh. Presentations were interactive and there was an opportunity for carers to chat over refreshments where a range of literature was on display.

Feedback
80% found the course content “very good” and 20% rated content as “good”.

Conclusion
Some caregivers perceive caring as a chronic stressor which can cause depression, insomnia and repeated infections. Life can be intense and unpredictable and is complicated with competing responsibilities. It is important to identify carers at risk and to provide help and support to improve their day to day well-being. The Lothian Pulmonary Rehab Service and Carers Of East Lothian successfully delivered a carer support programme which included disease information and a forum for discussion, advice and support.

Looking To The Future
• Follow “Carers (Scotland) Act 2016” which takes effect from April 2018 – making caring more sustainable
• Continue joint working with COEL – run a third East Lothian course in 2018
• Improve content and delivery - ask carers to identify their learning and support needs
• Midlothian PR staff to run a session in Bonnyrigg
• Encourage those who attended to join a COEL support group and East Lothian Breathe Easy.

References
The impact of caring for those with chronic obstructive pulmonary disease (COPD) on carers’ psychological well-being: a qualitative research

Impacts of COPD on family carers and supportive interventions: a systematic review

Assessing carer needs in chronic obstructive pulmonary disease
Rogers Jo & Vale R. Chronic Respiratory Disease 2017 July 11: 10.1186/s40099-017-0066-z

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