

Opinion

COPD self management and self care

People with COPD live with their slowly deteriorating condition over many decades. Of necessity, they and their family develop self-care strategies to deal as best they can with the tobacco dependence, increasing disability, unpredictable exacerbations, complex medication regimes, co-morbidity and social isolation. Health care professionals have a key role in promoting self-care and enabling patients to self-manage more effectively.¹

Supporting self-care involves offering:

- Information about lifestyle changes, use of medicines and achieving personal goals
- Specific advice on management of exacerbations
- Flexible access to healthcare services
- Opportunities for involvement with lay groups

Personal Care Plans and COPD Action Plans are tools designed to facilitate supported self-care.

Information for self-care

Effective self-care is underpinned by accurate and accessible information, tailored to the individuals' disability, relevant to their personal circumstances and sensitive to their preferences for knowledge and autonomy.¹ Key topics that people with COPD and their carers attending the National Strategy stakeholder meetings identified as important include:

- education about the disease
- management of breathlessness
- pharmacological treatments
- management of exacerbations
- psychological support
- guidance on welfare benefits

Education begins as soon as a diagnosis is made, and more information is provided as the disease progresses. Information will need to respond to the patients' changing circumstances (e.g. a patient may want information about available benefits when they retire). Healthcare professionals need to be sensitive to patients' diverse preferences for the amount and format of information they receive. Poor literacy skills are common in people with COPD because of the link with smoking and deprivation, so video information may be particularly appropriate. Useful information resources

- The British Lung Foundation website has written and video-recorded information on COPD. (http://www.lunguk.org). The section headed 'Lung Health' includes lifestyle advice, information about diagnostic tests, a link to the COPD Assessment Test, disease-specific information about COPD and a sensitively written page on 'the final stages of lung disease'
- Patient.co.uk (http://www.patient.co. uk) is an information source with leaflets about many of the common conditions encountered in primary care. As well as being available online it is integrated into some GP computer systems.
- NHS Choices is a portal for accessing extensive information on healthy lifestyles, specific diseases, available treatments, Map of Medicine guidelines, NHS services and currently recruiting trials. (http://www.nhs.uk).
- The Information Prescription is an NHS initiative which aims to collate information specifically tailored to the individual patients' needs. Ideally, a 'prescription' is compiled in discussion with a clinician able to identify and provide (or signpost) the topics and services of most relevance to the patient. An on-line version enables a patient to develop their own Information Prescription. (http://www. nhs.uk/Pathways/copd/Pages/InfoScr iptCreate.aspx)

Managing their condition Quitting smoking

Smoking status should be checked at every COPD review, and brief advice about quitting given to those continuing to struggle against their tobacco dependence.² Useful practical guidance for primary care clinicians on supporting quit attempts is available from http://www. theipcrg.org/display/RESSMO/Tackling+t he+smoking+epidemic

Eating well

Patients should be advised to maintain a

healthy weight. Obesity exacerbates breathlessness, and being underweight is a marker of a poor prognosis. Severe dyspnoea can make eating very tiring: small, easy to chew meals are recommended. Specialist dietary advice may be needed to address the problem of cachexia.

Remaining active

Physical activity encompasses both the regular regimes of exercise promoted by pulmonary rehabilitation, as well as increasing daily domestic and social activities. Patients should be encouraged to set their own goals as a target for improvement, and be supported to achieve these. The increasing breathlessness, reduced activity, and consequent deconditioning are not the only barriers to remaining active. Inappropriate housing (e.g top floor flats with no lifts) may mean that a patient is unnecessarily housebound. Patients reliant on ambulatory oxygen may need support to overcome public concerns about safety of taking cylinders into public buildings or on public transport. The European Lung Foundation Air Travel Database can provide useful information about European airlines' policies on in-flight oxygen. (http://www.european-lungfoundation.org)

Understanding medication

Patients should be given appropriate information about the medication which they are prescribed so that they understand how it can help them, when they should take it, and any safety concerns. It is self-evident that medications only work if they are taken and, in the case of inhalers, taken effectively. No inhaled drug should be prescribed without an assessment of inhaler technique. Reviewing technique annually is only helpful if action is taken to address problems: changing to an alternative device may be more effective than repeatedly correcting poor technique.

Self-management of exacerbations

A Cochrane review concluded that selfmanagement education reduces hospital admissions, significantly improves breathlessness and respiratory-related quality of life.³ An effective COPD 'action plan' including instructions about when and how to adjust and/or start medication in the event of an exacerbation should be introduced in the context of an educational programme. Figure 1 shows the Plymouth COPD Action Plan.

- Recognising deterioration: There are no physiological measures which reliably predict exacerbations, so typically patients are asked to monitor their symptoms (increased breathlessness, increased quantity and purulence of sputum).⁴ Tools such as sputum colour charts may help patients differentiate exacerbations from 'bad days' with COPD.
- Taking action: Patients vary in the degree of autonomy that they wish to accept, but most will be happy to keep emergency supplies of steroids and antibiotics, though some will prefer to talk with a clinician before commencing treatment. It is important to specify when to seek urgent clinical advice.

Self-management plans should be reviewed regularly and revised as the COPD progresses and management is stepped up.

Tele-monitoring, and COPD Healthy Outlook Programme (Met Office)

There is growing interest in the potential of tele-monitoring to support self-management especially in people at risk of acute exacerbations,⁵ though a recent trial showed no reduction in hospitalisation or improvement in quality of life.⁶ Other initiatives use data on pollution,⁷ and prevalent viruses combined with weather conditions⁸ to predict risk of exacerbations so that patients can be prepared.

Support for self-care

People with respiratory long-term conditions value the support of a trusted clinician.⁹ The organisation of healthcare services is crucial, specifically the flexibility of access to professional support.¹⁰ At the onset of an exacerbation, a prompt face-toface consultation may be required, on other occasions a brief telephone call or email communication may suffice to answer a question or reassure a patient that their self-management is appropriate.¹⁰ NHS choices includes web-based resources to support self-care.¹¹

Establishing relationships with other people with COPD is a recognised benefit of pulmonary rehabilitation, and many patients value the on-going support of their local BreatheEasy group.¹² 'Expert patient' courses aim to improve confidence in living with a long-term condition, and teach generic skills of relevance to people with COPD.¹³

C a r e r s have their own needs as they are involved for many years in the allencompassing role of supporting a relative with COPD, sharing the impact



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of the illness on all aspects of life.

Personalised Care Plans

All people with long-term conditions, including COPD, have the option of having a Personalised Care Plan (PCP).14 Importantly, plans are owned by the patient and have to be tailored to individual circumstances. Clearly, a plan appropriate to a middle-aged worker with mild COPD and minimal symptoms will be very different to that required by an elderly patient unable to leave home because of their breathlessness. A COPD action plan advising on emergency management is likely to be a core component of a PCP, but in complex situations plans would also include details of care services, social needs and, if relevant advanced care planning.

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