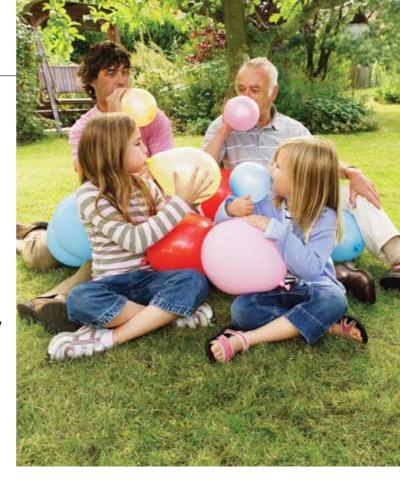
## **Partners** in COPD management in the primary care setting

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The development, integration and training of a team of partners in COPD care can reduce a patient's behavioural risk factors and optimise positive behaviour change.

## **KEY POINTS**

- · Primary care is the most appropriate setting to co-ordinate care for patients with COPD because it is widely accessible, person-centred and addresses both physical and emotional health needs.
- . An estimated 50% of patients with chronic disease do not adhere to recommended medications, and similar high rates of nonadherence have been reported in studies of patients with COPD.
- Practitioners should be aware of the significant impact of anxiety and depression on patients with COPD and encourage and facilitate patient engagement with effective treatments.
- Incorporating in practice the concepts of assessing readiness, tailoring information, assessing health literacy, motivational interviewing and goal setting to improve the outcomes of patients with COPD is encouraged.
- · Although patients' symptoms need to be well managed when end of life is approaching, it is also important to ensure personal, social and psychological support is in place.
- Carers of patients with COPD report that they would feel better equipped to perform their duties with education, inclusion and skills training.



hronic obstructive pulmonary disease (COPD) is a progressive and disabling respiratory disease affecting millions of people worldwide.1 Whereas no medical treatment can reverse COPD, multiple interventions are available that can reduce symptoms and functional impairments in daily life and increase (social) wellbeing and quality of life.1 Treatment choices depend not only on how the disease progresses, the presence of symptoms, the functional impairment and the diminished quality of life, but also on comorbidities and the capability of the patient to self-manage.<sup>2</sup>

Primary care practitioners are often confronted with patients with multimorbid chronic disease, and understand that the high prevalence of comorbidities such as cardiovascular diseases, diabetes, anxiety and depression in those with COPD demands a broader view than that of COPD alone. Primary care is the

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most appropriate setting to co-ordinate care for patients with COPD because it is widely accessible, person-centred and addresses both physical and emotional health needs.<sup>3</sup> The primary care interface not only provides the most logical opportunity for managing the progression of COPD in patients, from early diagnosis to end-of-life care, but also an appreciation of this illness in the context of other comorbidities and their psychosocial circumstances.

Comorbidities are the rule rather than the exception in COPD, 4.5 so specific interventions like smoking cessation, respiratory medications, oxygen therapy and pulmonary rehabilitation need to be supplemented with attention to other diseases as well as more generic and psychological support. The outcomes of respiratory and activity/exercise assessments together with mental health and other screening questionnaires can all guide the GP to make these treatment decisions.1 However, in this decision process consideration of the patient's beliefs and motivations as well as knowledge and health literacy is important. If a patient is unwilling to start a certain therapy or does not know why it is recommended or how best to use it, starting this treatment will most likely end in nonadherence and thus risk treatment failure. 6 Instead, efforts should be made to explore treatment barriers and, if possible, remove them. It is of utmost importance to make the patient a partner in care.7

With COPD, as with other chronic diseases, it is preferable that patients take responsibility for their lifestyle and at least part of their day-to-day treatment. Whereas some patients may have adapted adequately to their disease (e.g. made positive lifestyle changes), often this does not occur.8 Making lifestyle changes and taking responsibility for day-to-day treatment (e.g. proper inhalation of medication and self-treatment of exacerbations), as well as planning and enacting responses to both acute flare-ups (exacerbations) and advancing disablement, require patients to make behavioural changes.2 The use of behavioural change techniques becomes critical in increasing a patient's responsibility for their own health,9 and is an area in which an appropriately skilled practice nurse could have a key role.

In this article we discuss, in the context of COPD:

- how the patient can be motivated and trained to be a partner in their own care
- facilitators and barriers to patient adherence, using the example of mental health problems to elucidate the complexity of the relationship
- the role of behaviour change methods and identification of opportunities to apply these strategies in primary care
- practical measures for improving adherence and collaborative management
- the role of a team of health professionals and the carer in optimising effective partnerships at differing stages of care.

Optimal management of COPD incorporates the regular performance of health-related behaviours such as smoking cessation, appropriate use of medication, physical exercise, maintenance of a healthy diet and recognition of signs of exacerbation. Adherence to such management steps is a worldwide problem among those with chronic disease(s). A WHO study estimated that in developed countries about 50% of patients with chronic disease(s) do not adhere to recommended medications, 10 and a large meta-analysis evaluating data from 1948 to 1998 reported that approximately one in four patients were nonadherent. 11 Similar high rates of nonadherence have been reported in studies in patients with COPD. It is useful to consider contributing factors as those relating to the disease, the treatment, the patient and the relationship between healthcare provider and patient, as noted below.

- Disease characteristics acting as barriers to adherence include the progressive nature of the illness, poorer prognosis and a perceived absence of clinical symptoms. 12-16
- Treatment characteristics such as polypharmacy, higher dosing frequency, higher medication costs and side effects decrease adherence, whereas orally administered medication facilitates adherence.12-16
- In terms of patient characteristics, older age and better social support increase adherence, whereas better quality



Figure. Primary care is the most appropriate setting to co-ordinate care for patients with COPD as it is widely accessible, person-centred and addresses both physical and emotional health needs.

- of life, fewer clinical symptoms and the presence of psychiatric problems contribute to nonadherence. 12-16
- Aspects of the health provider-patient relationship that facilitate adherence include higher quality communication, hospitalisation, patient perception of clinician expertise, specialist care and closer follow up.12-16

Hence, clinician partners in care should be aware of the factors or strategies that may facilitate or hinder the required behaviour change associated with treatment adherence. The influence of partners in care in facilitating adherence also extends beyond the clinic, as shown in a recent study that found positive associations between the presence of a carer and adherence to medication, as well as success in smoking cessation.<sup>17</sup>

### Effects of anxiety and depression on adherence

The mental health status of the patient with COPD is a predictor of nonadherence as well as health outcomes. 18,19 The prevalence rates of anxiety and depression in patients with COPD are high. A recent review estimates that approximately 40% of patients with COPD experience clinical levels of anxiety and depression,<sup>20</sup> much higher than the global rate of less than 10% in the general population<sup>21</sup> and greater than in many other chronic diseases.<sup>22</sup>

Patients with COPD have a relative risk of 1.69 of developing depression.<sup>23</sup> This risk increases with COPD severity, with patients classified as having the most severe disease being twice as likely to be depressed than those with mild COPD.<sup>24</sup> It is not surprising, therefore, that depression is especially high among patients with COPD requiring oxygen<sup>25</sup> and at end-stage. <sup>22</sup> The relative risk of patients with COPD developing anxiety is 1.85.26 This risk is elevated further with an increase in disease severity, and dyspnoea in particular.<sup>26</sup> Furthermore, anxiety and depression often occur

together in both the general population and those with COPD, compounding the negative impact.27,28

Recent literature has focused on the negative impact of the comorbidities of anxiety and depression on the management of COPD. The presence of clinically significant symptoms of anxiety and/or depression is associated with reductions in adherence to treatment, 18,19 quality of life, 29 exercise capacity 30 and productivity,31 while also increasing the risk of exacerbation,32 healthcare utilisation,<sup>31,33</sup> disability and mortality.<sup>34,35</sup>

Despite the major impact of mental health problems on prognosis and adherence to management strategies by patients with COPD, anxiety and depression remain underdiagnosed and undertreated in this population.<sup>36</sup> Opportunities exist in the primary care setting to address these problems. To achieve better outcomes, doctors, nurses, allied health professionals and patients should be trained to recognise anxiety and depression symptoms. More routine screening for mental health issues may help to address the underdiagnosis of these problems among patients with COPD. Psychological distress screening tools such as the K10, Depression Anxiety Stress Scales (DASS), SPHERE and Patient Health Questionnaire-9 (PHQ-9) are recommended by peak primary and mental healthcare bodies and are brief and readily available for use in the primary care setting. 37,38

Providers should be aware of the significant impact of anxiety and depression on patients with COPD and encourage and facilitate patient engagement with effective treatments such as psychiatric medication, cognitive behavioural therapy, pulmonary rehabilitation and self-management approaches.<sup>36</sup> Since there is not always the capacity in general practice to implement such treatments, a concomitant increase in services from other primary or secondary care providers may be required. These include those available through the MBS (Better Access) initiative (access to psychiatrists, psychologists and mental health-trained GPs) and some chronic disease management and mental health programs administered by the Primary Health Networks.

### **Changing behaviour**

### Readiness for change

Numerous opportunities exist within the clinic to enable positive behaviour change. Primary care clinicians can assess 'readiness for change', a concept based on the Transtheoretical Stages of Change Model.<sup>39,40</sup> Health information and communication strategies can then be linked with tailored health intervention, which in turn can be customised to the readiness of the patient with COPD for change. Developers of the model propose that behaviour change interventions are more effective if stagematched and suggest the use of 'processes of change' (Table), a group of strategies to facilitate progression through the stages.<sup>40</sup> Readiness assists the uptake or reduction of target behaviours and is already widely used in smoking cessation and physical activity interventions.41

### Motivation

Although there is increased acknowledgement of the integral role of patient self-management, it is also known that the motivation of patients with COPD is associated with the success of these interventions. 42 Accordingly, recent approaches to behaviour change in COPD have used the strategy of motivational interviewing,43 an evidence-based, collaborative, person-centred method familiar to GPs that elicits and increases motivation for change.44-46 In COPD this approach has been linked with an improved therapeutic relationship between patient and interventionist, subsequently facilitating an increase in quality of life and patient acceptance.43

### **Health literacy**

An additional factor in the quality of the therapeutic relationship is the patient's level of health literacy, defined as the degree to which individuals have the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions.47 It includes a set of skills that influences the patient's motivation and ability to find, understand and effectively use health information.48 Low health literacy may lead to misunderstanding of instructions, which can impact on adherence to medical interventions. 49 Screening allows evaluation of the patient's health literacy as an asset to be used or a clinical risk to be addressed.<sup>48</sup> This assessment informs the tailoring of core messages and management strategies.48

### 5As framework

Primary healthcare practitioners are already familiar with the concepts of assessing readiness, tailoring information, assessing health literacy, motivational interviewing and goal setting as key components of the 5As framework for addressing behavioural risk factors (ask, advise, assess, assist and arrange),50 especially for cigarette smoking and assessing alcohol consumption. Incorporating

TABLE. 'PROCESSES OF CHANGE' AND THEIR RELATIONSHIP TO THE 'STAGES OF **CHANGE' MODEL\*** 

	of patients with COPD	Processes of change (in bold) with examples of use
Precontemplation	Not considering change	Consciousness raising Personalise risk and encourage self-exploration and re-evaluation of behaviour  Dramatic relief Explore issues of grief, loss and role changes from COPD Encourage the expression of feelings and solutions to reduce negative emotions Assess mental health Environmental re-evaluation Discuss the impact on valued others
Contemplation	Ambivalent regarding change	Self re-evaluation  Assess personal model of COPD/illness perception  Encourage evaluation of pros and cons of behaviour change  Identify and promote new, positive outcome expectancies
Preparation	Planning to act	Self and social liberation  Encourage belief that one can change; create conditions for change  Identify and assist in problem-solving obstacles  Identify social support  Verify that the patient has the skills for behaviour change  Encourage small initial steps
Action	Practising new behaviour	Use and foster social support and helping relationships  • Boost self-efficacy to enable contingency management  • Provide reinforcement for positive steps  Counter-conditioning  • Discuss substituting problem behaviours with positive ones  Stimulus control  • Discuss removing triggers/cues for unhealthy behaviours
Maintenance	Sustaining new behaviour	Continue positive reinforcement and social support  Reinforce internal rewards  Plan for follow-up support – institutional and social  Stimulus control  Discuss removing triggers/cues for unhealthy behaviours  Discuss relapse prevention  Maintain self-efficacy

these concepts to improve outcomes for patients with COPD (such as improved adherence to physical activity recommendations) is to be encouraged and supported.

### Patient-provider communication

Health practitioners may further facilitate patient adjustment by using principles drawn from psychological theories concerning behaviour change. Although there are numerous models (e.g. Social-Cognitive Theory, Health-Belief Model), good quality patient-provider communication is an essential key to the practical application of each of their principles. This communication facilitates model commonalities such as knowledge and understanding, personalisation, perceived susceptibility, beliefs, self-efficacy, intention, perceived resources and motivation. For example, patient concerns about COPD medications independently predicted nonadherence in a recent study.51

Illness perception is another prudent factor to consider in the communication process as it concerns how patients assess living with a disease.<sup>52</sup> It incorporates cognitive and emotional responses to perceived threat to one's health as well as cause, timeline, consequences, control and identity.<sup>53,54</sup> These perceptions can be modified by interactions with health practitioners, potentially restructuring the personal models of illness of the patient with COPD<sup>52</sup> and influencing adherence,<sup>51</sup> self-management and health-promoting behaviours such as attendance, and response to pulmonary rehabilitation. 55-57

Further examples can be seen in the personalisation of risk communication, which leads to more accurate risk perception, improved knowledge, increased uptake of screening tests and more informed patient decision making.58

Clinical guidelines for general practice have incorporated numerous practical applications of behaviour change models such as highlighting the benefits and costs of prevention and treatment strategies, patient involvement in decision making and emphasising the positive impact of effective doctor-patient interaction.<sup>59</sup>

### **End-of-life considerations**

Possibilities for positive influence on behaviour change remain relevant in the later stages of a patient's illness. Although a patient's symptoms need to be well managed when end of life is approaching, it is also important to ensure that personal, social and psychological support is in place. 60,61 Unfortunately, dying is often not discussed and, therefore, preparations for a 'good' death are not initiated,62 or start too late.60 Four reforms have been proposed to facilitate a comfortable death:

- there is more public discussion about the limits of health care as death approaches, and what we want for end of life
- personal wishes are defined
- assurances are made that personal wishes are respected
- services for those dying focus more on dying at home. 60 End-of-life care does not attempt to lengthen or shorten the

patient's life, but aims to optimise quality of life for the patient.<sup>63</sup> Consequently, topics such as prevention, cure and rehabilitation acquire less importance. 60 Discussion of end-of-life wishes could be initiated:

- during health assessments for people aged over 75 years
- as part of assessment and care planning for people in agedcare facilities and those receiving home-based care packages
- during hospital admissions of people who are assessed as likely to die in the next 12 months.60

Hospitalisations may be used as a screening tool for transition to palliative approaches in the community for patients late in the clinical course of COPD.<sup>64</sup> A simple tool, the Karnofsky Performance Status (KPS) scale, is often and effectively used in cancer care and palliative care, since progressively worsening scores on this scale are indicative of poorer prognosis. This tool can be easily applied to people with severe chronic disease; the Australian adaptation (AKPS) has been validated in the community setting in patients with various chronic diseases.65

GPs and their practice staff may find it useful to become familiar with the providers of their local palliative care services and find out what they can offer, in particular for their patients with endstage COPD.

### The importance of carers

A central partner in the management of COPD is the patient's carer. Family members and friends are the main providers of home care, with one study indicating that more than 70% of patients with COPD have at least one informal carer. 66 The presence of a carer has been linked with better treatment adherence, decreased smoking and fewer emergency visits by patients with COPD.<sup>17,67</sup>

Although the burden of this supportive role is significant and often neglected,68 carers themselves report that they would feel better equipped to perform their duties with education, inclusion and skill training.<sup>69</sup> Specifically, carers of patients with COPD have expressed the need for better understanding and training concerning the management of anxiety and panic, helpful and safe activities, quality of life facilitation and clarification regarding expectations for the future. 69 Older carers in particular have lower health literacy and less knowledge regarding COPD, and, therefore, they require more education on symptom management and pharmacological support.<sup>70</sup>

Carers' lack of understanding of the disease and prognostic uncertainty are impediments to symptom recognition and management in end-stage COPD.<sup>71</sup> Appropriate carer involvement and training may potentially address each of these needs and facilitate better patient management in the home. To this end, the COPD-X guidelines include carers at numerous points of management, such as discharge planning. Assessing the patient's readiness to go home should involve an evaluation of whether a carer is available as well as the carer's understanding and ability to administer medications.<sup>72</sup> It is at this point especially that communication between hospital care providers and the primary care team assumes even greater importance. This should not be seen as a one-way information street (from hospital staff to GP), but timely discussion among hospital and primary care staff as well as the carer and patient should be the invariable goal. Similar evaluation and integration of the carer can also occur in the primary care setting and clinicians may also assist carers with local support services, given the burden and distress often accompanying this role.68

### **Conclusion**

The development, integration and training of a team of partners in COPD care can reduce behavioural risk factors and optimise positive behaviour change. Opportunities within primary care will expand as practitioners within this setting recognise and value their potential role as behaviour-change agents. Teamwork with the patient, their carers and across providers and services allows further integration and consolidation of positive COPD management behaviours.

### References

A list of references is included in the website version of this article (www.medicinetoday.com.au).

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### References

- Global Initiative for Chronic Obstructive Lung Disease (GOLD). Global strategy for the diagnosis management and prevention of chronic obstructive pulmonary disease. GOLD; 2015.
- 2. Effing TW, Bourbeau J, Vercoulen J, et al. Self-management programmes for COPD: moving forward. Chron Respir Dis 2012; 9: 27-35.
- 3. European Academy of Teachers in General Practice. The European definition of general practice/family medicine. WONCA Europe; 2011.
- 4. Barnes PJ, Celli BR. Systemic manifestations and comorbidities of COPD. Eur Respir J 2009: 33: 1165-1185.
- 5. Anecchino C, Rossi E, Fanizza C, De Rosa M, Tognoni G, Romero M. Prevalence of chronic obstructive pulmonary disease and pattern of comorbidities in a general population. Int J Chron Obstruct Pulmon Dis 2007; 2: 567-574.
- 6. Sanduzzi A, Balbo P, Candoli P, et al. COPD: adherence to therapy. Multidiscip Respir Med 2014; 9: 60.
- Bourbeau J, Saad N. Integrated care model with self-management in chronic obstructive pulmonary disease: from family physicians to specialists. Chron Respir Dis 2013; 10: 99-105.
- 8. Vercoulen JH. A simple method to enable patient-tailored treatment and to motivate the patient to change behaviour. Chron Respir Dis 2012; 9: 259-268.
- 9. Schroeder SA. We can do better improving the health of the American people. N Engl J Med 2007; 357: 1221-1228.
- 10. World Health Organization (WHO). Adherence to long-term therapies: evidence for action. Geneva: WHO; 2003.
- 11. DiMatteo MR. Variations in patients' adherence to medical recommendations: a quantitative review of 50 years of research. Med Care 2004; 42: 200-209.
- 12. Agh T, Meszaros A. Adherence to therapy in chronic obstructive pulmonary disease. In: Ong KC, ed. Chronic obstructive pulmonary disease current concepts and practice. Croatia: InTech; 2012.
- 13. Restrepo RD, Alvarez MT, Wittnebel LD, et al. Medication adherence issues in patients treated for COPD. Int J Chron Obstruct Pulmon Dis 2008; 3: 371-384.
- 14. Bryant J, McDonald VM, Boyes A, Sanson-Fisher R, Paul C, Melville J. Improving medication adherence in chronic obstructive pulmonary disease: a systematic review. Respir Res 2013; 14: 109.
- 15. Cecere LM, Slatore CG, Uman JE, et al. Adherence to long-acting inhaled therapies among patients with chronic obstructive pulmonary disease (COPD). COPD 2012; 9: 251-258.
- 16. Charles MS, Blanchette CM, Silver H, Lavallee D, Dalal AA, Mapel D. Adherence to controller therapy for chronic obstructive pulmonary disease: a review. Curr Med Res Opin 2010; 26: 2421-2429.
- 17. Trivedi RB, Bryson CL, Udris E, Au DH. The influence of informal caregivers on

adherence in COPD patients. Ann Behav Med 2012; 44: 66-72.

18. Fan VS, Giardino ND, Blough DK, Kaplan RM, Ramsey SD. Costs of pulmonary rehabilitation and predictors of adherence in the National Emphysema Treatment Trial. COPD 2008; 5: 105-116.

19. Khdour MR, Hawwa AF, Kidney JC, Smyth BM, McElnay JC. Potential risk factors for medication non-adherence in patients with chronic obstructive pulmonary disease (COPD). Eur J Clin Pharmacol 2012; 68: 1365-1373.

- 20. Yohannes AM, Willgoss TG, Baldwin RC, Connolly MJ. Depression and anxiety in chronic heart failure and chronic obstructive pulmonary disease: prevalence, relevance, clinical implications and management principles. Int J Geriatr Psychiatry 2010; 25: 1209-1221.
- 21. Demyttenaere K, Bruffaerts R, Posada-Villa J, et al; WHO World Mental Health Survey Consortium. Prevalence, severity, and unmet need for treatment of mental disorders in the World Health Organization World Mental Health Surveys. JAMA 2004; 291: 2581-2590.
- 22. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. J Pain Symptom Manage 2006; 31: 58-69.
- 23. Atlantis E, Fahey P, Cochrane B, Smith S. Bidirectional associations between clinically relevant depression or anxiety and COPD: a systematic review and meta-analysis. Chest 2013; 144: 766-777.
- 24. Schneider C, Jick SS, Bothner U, Meier CR. COPD and the risk of depression. Chest 2010: 137: 341-347.
- 25. Lacasse Y, Rousseau L, Maltais F. Prevalence of depressive symptoms and depression in patients with severe oxygen-dependent chronic obstructive pulmonary disease. J Cardiopulm Rehabil 2001; 21: 80-86.
- 26. Eisner MD, Blanc PD, Yelin EH, et al. Influence of anxiety on health outcomes in COPD. Thorax 2010: 65: 229-234.
- Putman-Casdorph H, McCrone S. Chronic obstructive pulmonary disease, anxiety, and depression: state of the science. Heart Lung 2009; 38: 34-47.
   Willgoss TG, Yohannes AM. Anxiety disorders in patients with COPD: a systematic review. Respir Care 2013; 58: 858-866.
- 29. Tsiligianni I, Kocks J, Tzanakis N, Siafakas N, van der Molen T. Factors that influence disease-specific quality of life or health status in patients with COPD: a review and meta-analysis of Pearson correlations. Prim Care Respir J 2011;
- 30. Spruit MA, Watkins ML, Edwards LD, et al. Determinants of poor 6-min walking distance in patients with COPD: the ECLIPSE cohort. Respir Med 2010; 104: 849-857
- 31. Egede LE. Major depression in individuals with chronic medical disorders:

- prevalence, correlates and association with health resource utilization, lost productivity and functional disability. Gen Hosp Psychiatry 2007; 29: 409-416. 32. Laurin C, Moullec G, Bacon SL, Lavoie KL. Impact of anxiety and depression on chronic obstructive pulmonary disease exacerbation risk. Am J Respir Crit Care Med 2012; 185: 918-923.
- 33. Dalal AA, Shah M, Lunacsek O, Hanania NA. Clinical and economic burden of depression/anxiety in chronic obstructive pulmonary disease patients within a managed care population. COPD 2011; 8: 293-299.
- 34. Fan VS, Ramsey SD, Giardino ND, et al. Sex, depression, and risk of hospitalization and mortality in chronic obstructive pulmonary disease. Arch Intern Med 2007: 167: 2345-2353.
- 35. Ng TP, Niti M, Tan WC, Cao Z, Ong KC, Eng P. Depressive symptoms and chronic obstructive pulmonary disease: effect on mortality, hospital readmission, symptom burden, functional status, and quality of life. Arch Intern Med 2007; 167: 60-67
- 36. Cafarella PA, Effing TW, Usmani ZA, Frith PA. Treatments for anxiety and depression in patients with chronic obstructive pulmonary disease: a literature review. Respirology 2012; 17: 627-638.
- 37. Clarke D. beyondblue guide to the management of depression in primary care: a guide for health professionals. Hawthorn West, Vic: Beyond Blue Ltd; 2009. 38. Kyrios M, Mouding R, Nedeljkovic M. Anxiety disorders assessment and management in general practice. Aust Fam Physician 2011; 40: 370-374.
- 39. DiClemente CC, Prochaska JO. Self-change and therapy change of smoking behavior: a comparison of processes of change in cessation and maintenance. Addict Behav 1982; 7: 133-142.
- 40. Prochaska JO, Velicer WF. The transtheoretical model of health behavior change. Am J Health Promot 1997: 12: 38-48.
- 41. Coultas D, Russo R, Peoples J, et al. Improvements in self-efficacy and readiness to engage in physical activity are associated with improved health outcomes among patients with COPD. Eur Respir J 2014; 44(Suppl 58): 3489.
- 42. Bucknall CE, Miller G, Lloyd SM, et al. Glasgow supported self-management trial (GSuST) for patients with moderate to severe COPD: randomised controlled trial. BMJ 2012: 344: e1060.
- 43. Benzo R, Vickers K, Ernst D, Tucker S, McEvoy C, Lorig K. Development and feasibility of a self-management intervention for chronic obstructive pulmonary disease delivered with motivational interviewing strategies. J Cardiopulm Rehabil Prev 2013; 33: 113-123.
- 44. Miller WR, Rollnick S. Ten things that motivational interviewing is not. Behav Cogn Psychother 2009; 37: 129-140.
- 45. Rubak S, Sandbaek A, Lauritzen T, Christensen B. Motivational interviewing: a systematic review and meta-analysis. Br J Gen Pract 2005; 55: 305-312. 46. Rollnick S, Butler CC, Kinnersley P, Gregory J, Mash B. Motivational interviewing. BMJ 2010; 340: c1900.
- 47. Selden CR, Zorn MR, Ratzan S, Parker RM. Current bibliographies in medicine: health literacy. National Institutes of Health, National Library of Medicine; 2000. Available online at: www.nlm.nih.gov/archive//20061214/pubs/cbm/hliteracy. html (accessed July 2015).
- 48. Nutbeam D. The evolving concept of health literacy. Soc Sci Med 2008; 67: 2072-2078.
- 49. Roberts NJ, Ghiassi R, Partridge MR. Health literacy in COPD. Int J Chron Obstruct Pulmon Dis 2008; 3: 499-507.
- 50. Dosh SA, Holtrop JS, Torres T, Arnold AK, Baumann J, White LL. Changing organizational constructs into functional tools: an assessment of the 5 A's in primary care practices. Ann Fam Med 2005; 3 Suppl 2: S50-52.
- 51. Krauskopf K, Federman AD, Kale MS, et al. Chronic obstructive pulmonary disease illness and medication beliefs are associated with medication adherence. COPD 2015; 12: 151-164.
- 52. Borge CR, Moum T, Puline Lein M, Austegard EL, Wahl AK. Illness perception

- in people with chronic obstructive pulmonary disease. Scand J Psychol 2014; 55: 456-463
- 53. Cameron LD, Leventhal H. The self-regulation of health and illness behaviour: London and New York: Routledge; 2003.
- 54. Broadbent E, Petrie KJ, Main J, Weinman J. The brief illness perception questionnaire. J Psychosom Res 2006; 60: 631-637.
- 55. Kaptein AA, Scharloo M, Fischer MJ, et al. Illness perceptions and COPD: an emerging field for COPD patient management. J Asthma 2008; 45: 625-629. 56. Fischer MJ, Scharloo M, Abbink JJ, et al. Drop-out and attendance in pulmonary rehabilitation: the role of clinical and psychosocial variables. Respir
- Med 2009; 103: 1564-1571.

  57. Zoeckler N, Kenn K, Kuehl K, Stenzel N, Rief W. Illness perceptions predict
- exercise capacity and psychological well-being after pulmonary rehabilitation in COPD patients. J Psychosom Res 2014; 76: 146-151.
- 58. Edwards AG, Evans R, Dundon J, Haigh S, Hood K, Elwyn GJ. Personalised risk communication for informed decision making about taking screening tests.

  Cochrane Database Syst Rev 2006; (4): CD001865.
- 59. Royal Australian College of General Practitioners (RACGP). Guidelines for preventive activities in general practice, 8th ed. Melbourne: RACGP; 2012.
- 60. Swerissen H, Duckett SJ. What can we do to help Australians die the way they want to? Med J Aust 2015; 202: 10-11.
- 61. Holloway K, Toye C, McConigley R, Tieman J, Currow D, Hegarty M. National consultation informing development of guidelines for a palliative approach for aged care in the community setting. Australas J Ageing 2015; 34: 21-26.
- 62. Crawford GB, Brooksbank MA, Brown M, Burgess TA, Young M. Unmet needs of people with end-stage chronic obstructive pulmonary disease:
- recommendations for change in Australia. Intern Med J 2013; 43: 183-190.
- 63. Palliative Care Australia. A guide to palliative care service development: a population based approach. Deakin West, Vic: Palliative Care Australia; 2005.
- 64. Gavazzi A, De Maria R, Manzoli L, et al. Palliative needs for heart failure or chronic obstructive pulmonary disease: results of a multicenter observational registry. Int J Cardiol 2015; 184: 552-558.
- 65. Abernethy AP, Shelby-James T, Fazekas BS, Woods D, Currow DC. The Australia-modified Karnofsky Performance Status (AKPS) scale: a revised scale for contemporary palliative care clinical practice [ISRCTN81117481]. BMC Palliat Care 2005; 4: 7.
- 66. Gautun H, Werner A, Luras H. Care challenges for informal caregivers of chronically ill lung patients: results from a questionnaire survey. Scand J Public Health 2012; 40: 18-24.
- 67. Wakabayashi R, Motegi T, Yamada K, Ishii T, Gemma A, Kida K. Presence of in-home caregiver and health outcomes of older adults with chronic obstructive pulmonary disease. J Am Geriatr Soc 2011; 59: 44-49.
- 68. Miravitlles M, Pena-Longobardo LM, Oliva-Moreno J, Hidalgo-Vega A. Caregivers' burden in patients with COPD. Int J Chron Obstruct Pulmon Dis 2015; 10: 347-356.
- 69. Penfold C, Ewing G, Gilligan D, et al. What do informal carers want to learn about breathlessness in advanced disease and how do they want to learn it? BMJ Support Palliat Care 2015; 5: 107.
- 70. Hsiao PC, Chu CM, Sung PY, Perng WC, Wang KY. Differences in COPD patient care by primary family caregivers: an age-based study. PLoS One 2014; 9: e107870.
- 71. Pinnock H, Kendall M, Murray SA, et al. Living and dying with severe chronic obstructive pulmonary disease: multi-perspective longitudinal qualitative study. BMJ 2011: 342: d142.
- 72. Yang I, Dabscheck E, George J, et al. The COPD-X plan: Australian and New Zealand Guidelines for the management of chronic obstructive pulmonary disease 2015. Thoracic Society of Australia and New Zealand and Lung Foundation Australia. Available online at: http://copdx.org.au (accessed July 2015).