

## PERSPECTIVE OPEN

## A woman with asthma: a whole systems approach to supporting self-management

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A 35-year-old lady attends for review of her asthma following an acute exacerbation. There is an extensive evidence base for supported self-management for people living with asthma, and international and national guidelines emphasise the importance of providing a written asthma action plan. Effective implementation of this recommendation for the lady in this case study is considered from the perspective of a patient, healthcare professional, and the organisation. The patient emphasises the importance of developing a partnership based on honesty and trust, the need for adherence to monitoring and regular treatment, and involvement of family support. The professional considers the provision of asthma self-management in the context of a structured review, with a focus on a self-management discussion which elicits the patient's goals and preferences. The organisation has a crucial role in promoting, enabling and providing resources to support professionals to provide self-management. The patient's asthma control was assessed and management optimised in two structured reviews. Her goal was to avoid disruption to her work and her personalised action plan focused on achieving that goal.

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## CASE STUDY

A 35-year-old sales representative attends the practice for an asthma review. Her medical record notes that she has had asthma since childhood, and although for many months of the year her asthma is well controlled (when she often reduces or stops her inhaled steroids), she experiences one or two exacerbations a year requiring oral steroids. These are usually triggered by a viral upper respiratory infection, though last summer when the pollen count was particularly high she became tight chested and wheezy for a couple of weeks.

Her regular prescription is for fluticasone 100 mcg twice a day, and salbutamol as required. She has a young family and a busy lifestyle so does not often manage to find time to attend the asthma clinic. A few weeks previously, an asthma attack had interfered with some important work-related travel, and she has attended the clinic on this occasion to ask about how this can be managed better in the future. There is no record of her having been given an asthma action plan.

## WHAT DO WE KNOW ABOUT ASTHMA SELF-MANAGEMENT? THE ACADEMIC PERSPECTIVE

Supported self-management reduces asthma morbidity

The lady in this case study is struggling to maintain control of her asthma within the context of her busy professional and domestic life. The recent unfortunate experience which triggered this consultation offers a rare opportunity to engage with her and discuss how she can manage her asthma better. It behoves the clinician whom she is seeing (regardless of whether this is in a dedicated asthma clinic or an appointment in a routine general practice surgery) to grasp the opportunity and discuss self-management and provide her with a (written) personalised asthma action plan (PAAP).

The healthcare professional advising the lady is likely to be aware that international and national guidelines emphasise the importance of supporting self-management.<sup>1-4</sup> There is an extensive evidence base for asthma self-management: a recent synthesis identified 22 systematic reviews summarising data from 260 randomised controlled trials encompassing a broad range of demographic, clinical and healthcare contexts, which concluded that asthma self-management reduces emergency use of healthcare resources, including emergency department visits, hospital admissions and unscheduled consultations and improves markers of asthma control, including reduced symptoms and days off work, and improves quality of life.<sup>1,2,5-12</sup> Health economic analysis suggests that it is not only clinically effective, but also a cost-effective intervention.<sup>13</sup>

Personalised asthma action plans

Key features of effective self-management approaches are:

- Self-management education should be reinforced by provision of a (written) PAAP which reminds patients of their regular treatment, how to monitor and recognise that control is deteriorating and the action they should take.<sup>14-16</sup> As an adult, our patient can choose whether she wishes to monitor her control with symptoms or by recording peak flows (or a combination of both).<sup>6,8,9,14</sup> Symptom-based monitoring is generally better in children.<sup>15,16</sup>
- Plans should have between two and three action points including emergency doses of reliever medication; increasing low dose (or recommencing) inhaled steroids; or starting a course of oral steroids according to severity of the exacerbation.<sup>14</sup>
- Personalisation of the action plan is crucial. Focussing specifically on what actions she could take to prevent a

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**Box 1** What self-management help should this lady expect from her general practitioner or asthma nurse? The patient's perspective

- The first priority is that the patient is reassured that her condition can be managed successfully both in the short and the long term. A good working relationship with the health professional is essential to achieve this outcome. Developing trust between patient and healthcare professional is more likely to lead to the patient following the PAAP on a long-term basis.
- A review of all medication and possible alternative treatments should be discussed. The patient needs to understand why any changes are being made and when she can expect to see improvements in her condition. Be honest, as sometimes it will be necessary to adjust dosages before benefits are experienced. Be positive. 'There are a number of things we can do to try to reduce the impact of asthma on your daily life'. 'Preventer treatment can protect against the effect of pollen in the hay fever season'. If possible, the same healthcare professional should see the patient at all follow-up appointments as this builds trust and a feeling of working together to achieve the aim of better self-management.
- Is the healthcare professional sure that the patient knows how to take her medication and that it is taken at the same time each day? The patient needs to understand the benefit of such a routine. Medication taken regularly at the same time each day is part of any self-management regime. If the patient is unused to taking medication at the same time each day then keeping a record on paper or with an electronic device could help. Possibly the patient could be encouraged to set up a system of reminders by text or smartphone.
- Some people find having a peak flow meter useful. Knowing one's usual reading means that any fall can act as an early warning to put the PAAP into action. Patients need to be proactive here and take responsibility.
- Ongoing support is essential for this patient to ensure that she takes her medication appropriately. Someone needs to be available to answer questions and provide encouragement. This could be a doctor or a nurse or a pharmacist. Again, this is an example of the partnership needed to achieve good asthma control.
- It would also be useful at a future appointment to discuss the patient's lifestyle and work with her to reduce her stress. Feeling better would allow her to take simple steps such as taking exercise. It would also be helpful if all members of her family understood how to help her. Even young children can do this.
- From personal experience some people know how beneficial it is to feel they are in a partnership with their local practice and pharmacy. Being proactive produces dividends in asthma control.

repetition of the recent attack is likely to engage her interest. Not all patients will wish to start oral steroids without advice from a healthcare professional, though with her busy lifestyle and travel our patient is likely to be keen to have an emergency supply of prednisolone. Mobile technology has the potential to support self-management,<sup>17,18</sup> though a recent systematic review concluded that none of the currently available smart phone 'apps' were fit for purpose.<sup>19</sup>

- Identification and avoidance of her triggers is important. As pollen seems to be a trigger, management of allergic rhinitis needs to be discussed (and included in her action plan): she

may benefit from regular use of a nasal steroid spray during the season.<sup>20</sup>

- Self-management as recommended by guidelines,<sup>1,2</sup> focuses narrowly on adherence to medication/monitoring and the early recognition/remediation of exacerbations, summarised in (written) PAAPs. Patients, however, may want to discuss how to reduce the impact of asthma on their life more generally,<sup>21</sup> including non-pharmacological approaches.

**Supported self-management**

The impact is greater if self-management education is delivered within a comprehensive programme of accessible, proactive asthma care,<sup>22</sup> and needs to be supported by ongoing regular review.<sup>6</sup> With her busy lifestyle, our patient may be reluctant to attend follow-up appointments, and once her asthma is controlled it may be possible to make convenient arrangements for professional review perhaps by telephone,<sup>23,24</sup> or e-mail. Flexible access to professional advice (e.g., utilising diverse modes of consultation) is an important component of supporting self-management.<sup>25</sup>

**The challenge of implementation**

Implementation of self-management, however, remains poor in routine clinical practice. A recent Asthma UK web-survey estimated that only 24% of people with asthma in the UK currently have a PAAP,<sup>26</sup> with similar figures from Sweden<sup>27</sup> and Australia.<sup>28</sup> The general practitioner may feel that they do not have time to discuss self-management in a routine surgery appointment, or may not have a supply of paper-based PAAPs readily available.<sup>29</sup> However, as our patient rarely finds time to attend the practice, inviting her to make an appointment for a future clinic is likely to be unsuccessful and the opportunity to provide the help she needs will be missed.

**The solution will need a whole systems approach**

A systematic meta-review of implementing supported self-management in long-term conditions (including asthma) concluded that effective implementation was multifaceted and multidisciplinary; engaging patients, training and motivating professionals within the context of an organisation which actively supported self-management.<sup>5</sup> This whole systems approach considers that although patient education, professional training and organisational support are all essential components of successful support, they are rarely effective in isolation.<sup>30</sup> A systematic review of interventions that promote provision/use of PAAPs highlighted the importance of organisational systems (e.g., sending blank PAAPs with recall reminders).<sup>31</sup> A patient offers her perspective (Box 1), a healthcare professional considers the clinical challenge, and the challenges are discussed from an organisational perspective.

**WHAT ARE THE CLINICAL CHALLENGES FOR THE HEALTHCARE PROFESSIONAL IN PROVIDING SELF-MANAGEMENT SUPPORT?**

Due to the variable nature of asthma, a long-standing history may mean that the frequency and severity of symptoms, as well as what triggers them, may have changed over time.<sup>32</sup> Exacerbations requiring oral steroids, interrupting periods of 'stability', indicate the need for re-assessment of the patient's clinical as well as educational needs. The patient's perception of stability may be at odds with the clinical definition<sup>1,33</sup>—a check on the number of short-acting bronchodilator inhalers the patient has used over a specific period of time is a good indication of control.<sup>34</sup> Assessment of asthma control should be carried out using objective tools such as the Asthma Control Test or the Royal College of Physicians three questions.<sup>35,36</sup> However, it is important to remember that these assessment tools are not an end in

themselves but should be a springboard for further discussion on the nature and pattern of symptoms. Balancing work with family can often make it difficult to find the time to attend a review of asthma particularly when the patient feels well. The practice should consider utilising other means of communication to maintain contact with patients, encouraging them to come in when a problem is highlighted.<sup>37,38</sup> Asthma guidelines advocate a structured approach to ensure the patient is reviewed regularly and recommend a detailed assessment to enable development of an appropriate patient-centred (self)management strategy.<sup>1-4</sup>

Although self-management plans have been shown to be successful for reducing the impact of asthma,<sup>21,39</sup> the complexity of managing such a fluctuating disease on a day-to-day basis is challenging. During an asthma review, there is an opportunity to work with the patient to try to identify what triggers their symptoms and any actions that may help improve or maintain control.<sup>38</sup> An integral part of personalised self-management education is the written PAAP, which gives the patient the knowledge to respond to the changes in symptoms and ensures they maintain control of their asthma within predetermined parameters.<sup>9,40</sup> The PAAP should include details on how to monitor asthma, recognise symptoms, how to alter medication and what to do if the symptoms do not improve. The plan should include details on the treatment to be taken when asthma is well controlled, and how to adjust it when the symptoms are mild, moderate or severe. These action plans need to be developed between the doctor, nurse or asthma educator and the patient during the review and should be frequently reviewed and updated in partnership (see Box 1). Patient preference as well as clinical features such as whether she under- or over-perceives her symptoms should be taken into account when deciding whether the action plan is peak flow or symptom-driven. Our patient has a lot to gain from having an action plan. She has poorly controlled asthma and her lifestyle means that she will probably see different doctors (depending who is available) when she needs help. Being empowered to self-manage could make a big difference to her asthma control and the impact it has on her life.

The practice should have protocols in place, underpinned by specific training to support asthma self-management. As well as ensuring that healthcare professionals have appropriate skills, this should include training for reception staff so that they know what action to take if a patient telephones to say they are having an asthma attack.

However, focusing solely on symptom management strategies (actions) to follow in the presence of deteriorating symptoms fails to incorporate the patients' wider views of asthma, its management within the context of her/his life, and their personal asthma management strategies.<sup>41</sup> This may result in a failure to use plans to maximise their health potential.<sup>21,42</sup> A self-management strategy leading to improved outcomes requires a high level of patient self-efficacy,<sup>43</sup> a meaningful partnership between the patient and the supporting health professional,<sup>42,44</sup> and a focused self-management discussion.<sup>14</sup>

Central to both the effectiveness and personalisation of action plans,<sup>43,45</sup> in particular the likelihood that the plan will lead to changes in patients' day-to-day self-management behaviours,<sup>45</sup> is the identification of goals. Goals are more likely to be achieved when they are specific, important to patients, collaboratively set and there is a belief that these can be achieved. Success depends on motivation<sup>44,46</sup> to engage in a specific behaviour to achieve a valued outcome (goal) and the ability to translate the behavioural intention into action.<sup>47</sup> Action and coping planning increases the likelihood that patient behaviour will actually change.<sup>44,46,47</sup> Our patient has a goal: she wants to avoid having her work disrupted by her asthma. Her personalised action plan needs to explicitly focus on achieving that goal.

As providers of self-management support, health professionals must work with patients to identify goals (valued outcomes) that are important to patients, that may be achievable and with which they can engage. The identification of specific, personalised goals and associated feasible behaviours is a prerequisite for the creation of asthma self-management plans. Divergent perceptions of asthma and how to manage it, and a mismatch between what patients want/need from these plans and what is provided by professionals are barriers to success.<sup>41,42</sup>

#### WHAT ARE THE CHALLENGES FOR THE HEALTHCARE ORGANISATION IN PROVIDING SELF-MANAGEMENT SUPPORT?

A number of studies have demonstrated the challenges for primary care physicians in providing ongoing support for people with asthma.<sup>31,48,49</sup> In some countries, nurses and other allied health professionals have been trained as asthma educators and monitor people with stable asthma. These resources are not always available. In addition, some primary care services are delivered in constrained systems where only a few minutes are available to the practitioner in a consultation, or where only a limited range of asthma medicines are available or affordable.<sup>50</sup>

There is recognition that the delivery of quality care depends on the competence of the doctor (and supporting health professionals), the relationship between the care providers and care recipients, and the quality of the environment in which care is delivered.<sup>51</sup> This includes societal expectations, health literacy and financial drivers.

In 2001, the Australian Government adopted a programme developed by the General Practitioner Asthma Group of the National Asthma Council Australia that provided a structured approach to the implementation of asthma management guidelines in a primary care setting.<sup>52</sup> Patients with moderate-to-severe asthma were eligible to participate. The 3+ visit plan required confirmation of asthma diagnosis, spirometry if appropriate, assessment of trigger factors, consideration of medication and patient self-management education including provision of a written PAAP. These elements, including regular medical review, were delivered over three visits. Evaluation demonstrated that the programme was beneficial but that it was difficult to complete the third visit in the programme.<sup>53-55</sup> Accordingly, the programme, renamed the Asthma Cycle of Care, was modified to incorporate two visits.<sup>56</sup> Financial incentives are provided to practices for each patient who receives this service each year.

Concurrently, other programmes were implemented which support practice-based care. Since 2002, the National Asthma Council has provided best-practice asthma and respiratory management education to health professionals,<sup>57</sup> and this programme will be continuing to 2017. The general practitioner and allied health professional trainers travel the country to provide asthma and COPD updates to groups of doctors, nurses and community pharmacists. A number of online modules are also provided. The PACE (Physician Asthma Care Education) programme developed by Noreen Clark has also been adapted to the Australian healthcare system.<sup>58</sup> In addition, a pharmacy-based intervention has been trialled and implemented.<sup>59</sup>

To support these programmes, the National Asthma Council ([www.nationalasthma.org.au](http://www.nationalasthma.org.au)) has developed resources for use in practices. A strong emphasis has been on the availability of a range of PAAPs (including plans for using adjustable maintenance dosing with ICS/LABA combination inhalers), plans for indigenous Australians, paediatric plans and plans translated into nine languages. PAAPs embedded in practice computer systems are readily available in consultations, and there are easily accessible online paediatric PAAPs (<http://digitalmedia.sahealth.sa.gov.au/public/asthma/>). A software package, developed in the UK, can be downloaded and used to generate a pictorial PAAP within the consultation.<sup>60</sup>

One of the strongest drivers towards the provision of written asthma action plans in Australia has been the Asthma Friendly Schools programme.<sup>61,62</sup> Established with Australian Government funding and the co-operation of Education Departments of each state, the Asthma Friendly Schools programme engages schools to address and satisfy a set of criteria that establishes an asthma-friendly environment. As part of accreditation, the school requires that each child with asthma should have a written PAAP prepared by their doctor to assist (trained) staff in managing a child with asthma at school.

### THE CASE STUDY CONTINUES...

The initial presentation some weeks ago was during an exacerbation of asthma, which may not be the best time to educate a patient. It is, however, a splendid time to build on their motivation to feel better. She agreed to return after her asthma had settled to look more closely at her asthma control, and an appointment was made for a routine review.

At this follow-up consultation, the patient's diagnosis was reviewed and confirmed and her trigger factors discussed. For this lady, respiratory tract infections are the usual trigger but allergic factors during times of high pollen count may also be relevant. Assessment of her nasal airway suggested that she would benefit from better control of allergic rhinitis. Other factors were discussed, as many patients are unaware that changes in air temperature, exercise and pets can also trigger asthma exacerbations. In addition, use of the Asthma Control Test was useful as an objective assessment of control as well as helping her realise what her life could be like! Many people with long-term asthma live their life within the constraints of their illness, accepting that is all that they can do.

After assessing the level of asthma control, a discussion about management options—trigger avoidance, exercise and medicines—led to the development of a written PAAP. Asthma can affect the whole family, and ways were explored that could help her family understand why it is important that she finds time in the busy domestic schedules to take her regular medication. Family and friends can also help by understanding what triggers her asthma so that they can avoid exposing her to perfumes, pollens or pets that risk triggering her symptoms. Information from the national patient organisation was provided to reinforce the messages.

The patient agreed to return in a couple of weeks, and a recall reminder was set up. At the second consultation, the level of control since the last visit will be explored including repeat spirometry, if appropriate. Further education about the pathophysiology of asthma and how to recognise early warning signs of loss of control can be given. Device use will be reassessed and the PAAP reviewed. Our patient's goal is to avoid disruption to her work and her PAAP will focus on achieving that goal. Finally, agreement will be reached with the patient about future routine reviews, which, now that she has a written PAAP, could be scheduled by telephone if all is well, or face-to-face if a change in her clinical condition necessitates a more comprehensive review.

### COMPETING INTERESTS

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