



# **Asthma Adherence**

## **A Guide for Health Professionals**

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## Foreword

Asthma management has continued to improve in Australia, and health professionals are now caring for people with asthma with more information, skills and sophisticated medications at their disposal than ever before. However, adherence to medication regimens and lifestyle advice can still be difficult for many patients, despite ever-increasing amounts of information and the efforts of doctors, pharmacists, asthma educators and nurses to improve their communication skills.

The challenges of modern medicine, in particular the management of such complex diseases as asthma, make teamwork essential if any healthcare strategy is to succeed. The achievements of the National Asthma Council in bringing together the various partners in asthma in a concerted effort are well known. Further progress depends on more effectively including the patient in that partnership.

Understanding the barriers to adherence, and encouraging appropriate self-care and commitment in a true partnership with the patient, is essential. Health professionals need the ability to assess and equip patients for improved self-management using adherence strategies for which there is a growing evidence base.

Asthma, as a chronic illness with acute phases, presents special challenges. Overcoming the health beliefs that can lead to denial of the condition, countering the negative connotations and dealing with the psychosocial issues of taking long-term medication can be daunting tasks for those of us whose main training has been as clinicians rather than psychologists or behaviouralists. This guide attempts to redress that imbalance by providing practical, targeted and succinct information on managing these issues.

The advice and strategies contained in this guide should be useful across a range of chronic conditions; their range is not confined to asthma. The Department of Health and Aged Care is pleased to have supported this publication and I hope that it will stimulate new relationships between professionals and people with asthma, leading to improved health outcomes.



Dr Michael Wooldridge  
Minister for Health and Aged Care

## Preface

This guide has been produced as a result of the National Asthma Campaign's (now National Asthma Council) Asthma Adherence Workshop, held in June 1997 and funded by the Commonwealth Department of Health and Aged Care. Compliance, or rather adherence, was seen as an issue in asthma care that had not at that time been effectively addressed, despite the progress made in clinical asthma management and the provision of information to people with asthma.

Participants and speakers at the workshop were invited on the basis of their special interest, experience or expertise in the area of patient adherence to medication regimens, and included clinicians, researchers, educators and behaviouralists. The workshop was designed to present contemporary practice and theory in a manner that would encourage interaction and thoughtful discussion, with the goal of developing practical strategies to improve asthma adherence. A key recommendation was the development of an asthma adherence guide for those involved in asthma management, including doctors, pharmacists and asthma educators.

The planning committee for the Adherence Workshop, together with several of the presenters, subsequently became the reference group for this project. Recent Australian and international literature on adherence was drawn on extensively by the group. The National Asthma Campaign's Asthma Adherence Workshop Report (1997) has also been used in the development of the text.

Asthma Adherence Reference Group members were:

Prof. Adrian Bauman, Professor of Public Health, Department of Epidemiology, Liverpool Hospital, NSW

Dr Ron Borland, Deputy Director, Centre for Behavioural Research in Cancer, VIC

Dr Chris Brown, general practitioner, QLD

Dr Jill Cockburn, Head, Discipline of Behavioural Science, Faculty of Medicine and Health Sciences, University of Newcastle, NSW

Dr David Hill, Director, Centre for Behavioural Research in Cancer, VIC

Assoc. Prof. Cynthia Rand, Associate Professor of Medicine, The Johns Hopkins Asthma and Allergy Centre, Johns Hopkins University, Baltimore, MA, USA

Dr Colin Robertson, Deputy Director, Department of Respiratory Medicine, Royal Children's Hospital, VIC

Assoc. Prof. Susan Sawyer, Deputy Director, Centre for Adolescent Health, VIC

Dr Kay Stewart, Senior Lecturer in Pharmacy Practice, Victorian College of Pharmacy, Monash University, VIC

Mr Brett Toelle, Research Officer, Institute of Respiratory Medicine, University of Sydney, NSW

We would also like to acknowledge the contribution of Ms Felicity Finlayson and Ms Adrienne James of the Lung Health Promotion Centre at The Alfred Hospital, Melbourne. The Alfred's Asthma Education Profile Questionnaire, and the Behavior Change Protocol, are reproduced with permission.

We are grateful to Emeritus Professor Philip Ley for his encouragement and advice on adherence issues.

# Introduction

It is now clear that adherence is an issue that must be addressed by health professionals concerned to improve both the quality of life and the health outcomes of their patients or clients.

International literature suggests that 50% of people who suffer from chronic disease do not adhere to their treatment regimen and therefore do not derive optimum benefits (Royal Pharmaceutical Society 1997). A telling fact is that 50% of patients leave their GP's office without even knowing what they have been told to do (DiMatteo 1994).

Adherence to prescribed therapy has been identified as a major factor in successful asthma management (Rand 1997). However, in spite of the significant advances in developing asthma medications and the introduction of Asthma Management Plans, it appears that many people with asthma are unable to manage their therapy to best effect.

In developing this practical guide the National Asthma Council (NAC) aims to assist those involved in asthma care to understand more about adherence and the factors affecting it, both as a patient issue and an asthma management issue. It has been written to complement the *Asthma Management Handbook*.

Health professionals need to gain a complete understanding of adherence and the multitude of factors that contribute to poor adherence, in order to be able to assess levels of adherence and implement strategies to improve patient self-management and health outcomes.

## Structure of this guide

Section I explores the question, 'what do we mean by adherence?' This gives a broad overview of the many factors influencing adherence and presents adherence as a dynamic and complex process, which goes far beyond the correct use of prescribed medication.

Section II is largely evidence-based, and uses the international literature to identify the major influences on adherence.

Section III explores ways in which health professionals can act to improve adherence, and suggests some strategies for dealing with patients. Practical suggestions for improving adherence can be found. A set of frequently asked questions and answers is also included. Finally, we have included tools such as a questionnaire and behaviour change protocol to assist you in assessing and addressing the issue of adherence.

## Asthma at a glance

- Over two million Australians have asthma, including:
  - one in four primary school children
  - one in seven teenagers
  - one in ten adults
- Asthma currently costs the Australian community between \$585 and \$720 million annually.
- Asthma is one of the ten most common reasons for seeing a general practitioner.

## Approach of this guide

The intent of this guide is to help members of the asthma care team - doctors, pharmacists, nurses, asthma educators - to better understand issues relating to adherence and to provide some practical suggestions for modifying your practices to assist patients to improve adherence to their management regimen.

We take an evidence-based approach, drawing broadly on the published literature to understand the nature of the problem and to identify and work towards some of the possible solutions.

This guide is based on the belief that the health professional has a vital role to play in improving asthma adherence, and that a new approach to relationships with patients needs to be fostered if we are to successfully combat non-adherence.

In a recent research study, the doctor/patient relationship was cited as an important predictor of adherence (Toelle, Peat & Dunn 1998). The two most important elements of this relationship are **communication** and **partnership**. Adopting a more interactive, non-judgmental and patient-centred approach will help to establish a more open relationship with your patient. Good communication is vital in order to make a proper assessment of a patient's capacity or willingness to adhere to treatment, and to identify possible barriers to

adherence.

'...the most salient and prevalent influences on medicine taking are the beliefs that people hold about their medication and about medicines in general. These beliefs are often at variance with the best evidence from medical science and consequently receive scant, if any, attention from the prescriber. Yet they are firmly rooted in the personal and family and cultural experiences of us all. For the prescriber simply to reaffirm the views of medical science, and to dismiss and ignore these beliefs, is to fail to prescribe effectively.'

(Royal Pharmaceutical Society 1997)

As we will explore in this guide, adherence is influenced by many factors:

- the patient's attitude towards their asthma
- the priority of health in their life
- their health beliefs
- prior experiences
- complexity of life at time of consultation
- understanding of the disease
- self-efficacy

It is not possible to elicit this information from your patient when working within a strictly medical model, or acting in the role of educator or instructor. Adopting a partnership approach allows you to blend the ideal management plan with the patient's perspective, situation and goals.

A patient's motivation, beliefs and capacities in relation to medicine-taking or self-management are major influences on adherence. However, just as important is the health professional's identification and recognition of the importance of these influences. Partnership and communication are vital in any successful intervention.

'The doctor/patient relationship is the pivotal link in influencing patient behaviour change. The principal determinant of best health outcomes of asthmatics was a partnership relationship with a doctor.'

(Anderson 1997)

## Terminology

The terminology used in asthma management is more than a collection of useful words that has currency amongst health professionals. In the case of this guide it says something about the relationship between the health professional, the patient and the treatment or management regimen.

The evolution of the role of the health professional in asthma management from instructor to partner can be seen in the changing terminology:

compliance → adherence → concordance

**Compliance** implies that the patient will follow doctor's orders, is in a less informed position and has little or no input into their management strategy.

**Adherence** focuses more on commitment to the regimen where the therapy is the controlling factor. There is at least reasonable negotiation between members of the asthma care team and the person with asthma.

**Concordance** is based on a notion of equality and respect for the patient and their autonomy, the desired relationship in a therapeutic alliance between the care team and person with asthma.

We have chosen to use the term adherence in this guide. While recognising that it falls short of the desirable relationship implicit in concordance, it is the term most commonly used in the current literature drawn on for

this guide, and a term with which most practitioners are comfortable.

With its focus on redefining relationships, suggesting strategies for more open communication, collaboration and partnerships, this guide promotes the spirit of concordance. The key intention of this guide is not simply to achieve better compliance with medications, or improved adherence to management plans, although of course these are vitally important. The aim is to educate and encourage health professionals to take part in concordant partnerships, so that treatment and management of asthma is informed by scientific evidence, as well as being consonant with patients' perceptions and wishes. The ultimate goal is to improve patients' quality of life and health outcomes.

Poor adherence is nothing new. Around 200 BC, Hippocrates advised the physician,

'...to be alert to the faults of the patients which make them lie about their taking of the medicines prescribed and when things go wrong, refuse to confess that they have not been taking their medicine.'

# Section I - What we mean by Adherence

Although compliance with the prescribed therapy is the cornerstone of effective asthma management, we need to keep in mind that adherence is a much more complex and broad concept than correct use of medication. This section attempts to widen the definition of adherence and identify the multitude of issues associated with the concept.

## The Nature of Adherence

Adherence needs to be redefined from being a static concept to a dynamic process (Campbell 1997). Adherence is never static, and is affected by such factors as the different medications prescribed, the duration of treatment, the length of time between visits to the doctor, the patient's daily schedule, family situation, and so on.

### Adherence with the Australian Asthma Management Plan

A recent qualitative study investigated patients' adherence to their management plans. It found that there are different levels of adherence to, and different attitudes towards, different elements:

- Avoidance of trigger factors was reported as the easiest component to follow.
- Peak flow monitoring was not considered to be an important component of asthma management.

(Toelle, Peat & Dunn 1998)

It is a widely held belief that adherence decreases over time, and that adherence with acute medication (e.g., 10 days' treatment with antibiotics) is far more likely to be successful than medication given on a longer term, as with asthma. However, it should be noted that adherence rates can be very low even for very acute interventions.

In various different study populations, adherence with 10 days' antibiotics has been demonstrated to be as low as 5% in some patients, to around 63% in others. In one study, 56% had stopped penicillin by Day 3 and 83% stopped by Day 9 of a 10-day course (Bergman & Werner 1963).

## Adherence to What

Medication is only one aspect of adherence, particularly in the case of asthma management. As health professionals, we ask patients with asthma to adhere to a set of complex interrelated behaviours, including:

- medication compliance
- compliance with a written management plan,
- including attendance at follow-up appointments
- allergy and trigger factor avoidance strategies
- peak flow monitoring
- medication use techniques
- recording of symptoms
- regular review

## Patterns of Adherence

There are several types of non-adherence, as well as degrees or levels of adherence. Researchers have developed the following categories of non-adherence:

**Primary** - when the patient does not get the prescription filled or fails to attend an appointment

**Secondary** - when the treatment is not taken as prescribed

**Intentional** - when the patient rejects the diagnosis or treatment

With this type of non-adherence, communication with patients is vital in order to understand their health beliefs, their feelings about their asthma and medications, and the barriers to adherence and conflicting priorities which lead patients actively to reject treatment.

**Unintentional** - may be due to a range of factors, but not planned, e.g. the patient would have taken the medication but they ran out, forgot it at home, stayed at a friend's house etc.

Unintentional poor adherence is the area most strongly linked to a large number of demographic, social, or clinical variables and influences, which will be discussed in Section II.

## Why is Adherence a Problem

Just as there are different patterns of poor adherence, there is an even broader range of factors and influences acting on patients who don't satisfactorily adhere to treatment. The medical argument for adherence is only one influence upon patients, and it competes with personal, social, cultural and lifestyle factors which are constantly influencing the patient and their behaviour and choices in relation to managing their health. This guide will go on to look more closely at these influences on adherence in the next section.

Every patient is different in their beliefs about their health and their asthma, their daily routine, their aspirations and goals, and their capacity to adhere. The complex set of factors which influences a patient's ability or desire to adhere is also constantly shifting over time, with the patient's changing circumstances and the level of severity of their asthma. This is why health professionals need to expand their traditional roles as diagnosticians, educators, or physicians, and work on improving their skills as communicators.

At the most basic level, poor communication skills can lead to a patient not understanding what they need to do in order to adhere. The patient's language and literacy skills, their cultural background, and age all need to be kept in mind when giving advice, prescribing or dispensing medication or providing education about asthma.

Patients typically only follow recommendations they really believe in and those they actually have the ability to carry out (DiMatteo 1994). Sometimes patients need practical help to develop the necessary skills to remember to take their medication, or to avoid their trigger factors. The more complex the treatment regimen, the easier it is for the patient to make a mistake and unintentionally not adhere. Factors such as the patient's age, daily schedule, and number of other medications being taken for other complaints can make the task of adhering to their management plan more difficult. Later, we discuss practical strategies such as reminders and written information to help combat non-adherence.

Perhaps the most important information which can be gained from better communication is the patient's attitude to their health and their asthma. Do they think it's worthwhile to adhere at all? The consequences of poor adherence may not be seen as negative by some patients, when compared with the perceived costs of good adherence, such as reduced spontaneity, or disruption to established routines. Many people who live with severe asthma symptoms for a long time forget what good health feels like and accept a health status that, to health professionals, seems far less than optimal.

## Adherence: Whose Responsibility

Adherence and self-management are the joint responsibility of the patient and members of the asthma care team. The latter have a responsibility to ensure that the patient is receiving the best possible treatment, education, and advice to facilitate a good level of adherence. Poor adherence is far more than simply the patient's fault, and it is now generally accepted that the responsibility for promoting better adherence lies with the health professional (Sawyer 1998). With positive, open and non-judgmental relationships, both health professionals and patients can keep to their part of the 'contract of care'.

The past ten years have seen a more collaborative team approach to patient care, and asthma management is no exception. General practitioners, pharmacists, asthma educators and nurses all have vital roles and responsibilities in improving patient adherence and asthma management.



## How Much Adherence is Enough

The question of how much adherence is enough is difficult to answer. Of course 100% adherence is the ideal, but for most people, complete adherence is not necessary to successfully manage their asthma to a level that enables them to achieve their personal goals and chosen activities in life.

### A Therapeutic Alliance

'The task of the patient is to convey her or his health beliefs to the doctor; and of the doctor, to enable this to happen. The task of the doctor or other prescriber is to convey his or her (professionally informed) health beliefs to the patient; and of the patient, to entertain these. The intention is to assist the patient to make as informed a choice as possible about the diagnosis and treatment, about benefit and risk and to take full part in a therapeutic alliance. Although reciprocal, this is an alliance in which the most important determinations are agreed to be those that are made by the patient.'

(Royal Pharmaceutical Society 1997)

Not all drugs rely on adherence to the same extent in producing effective responses. Some regimens are more flexible than others. It is perhaps self-evident that poor adherence begins to affect clinical outcomes when it reaches 'the point below which the desired preventive or therapeutic result is unlikely to be achieved' (Gordis 1976). There is no measurable level which applies universally. Each case must be assessed on its own merits, for example, the type of medication prescribed, the lifestyle, goals, and capacities of the patient.

For each patient, you should consider what they are losing when they deviate from their treatment regimen. What are the effects of the patient's poor adherence? Are they severe enough or inconvenient enough to modify the patient's behaviour, with help from you or other health professionals? Minimum levels or basic requirements should be discussed, in consultation with your patient. A better understanding of your patient and their situation may not achieve 100% adherence, but will improve adherence along with their quality of life and health outcomes.

## Benefits of Adherence

If health professionals and patients can work together to improve adherence, the benefits will be felt at all levels of society. Patients have the most to gain from improving their adherence to asthma management plans and treatment regimens. Health professionals know that use of preventive strategies leads to improved health outcomes. From the patient's point of view, proper adherence can mean a symptom-free existence, with a dramatically improved quality of life. Being able to control their asthma gives people a greater capacity to take part in their chosen activities, and achieve their goals.

The challenge for health professionals is to convey the potential benefits of improving adherence to prescribed therapy. The asthma care team will gain satisfaction from knowing they are making a real difference, and taking part in a successful therapeutic alliance that is reducing the cost of asthma to individuals and the community. There is evidence that the positive, communicative approach being advocated in this guide leads to better health outcomes, more satisfied patients and shorter consultations (Clark et al 1995).

The community will benefit by adherence in having more fully participative members of society, who are not disadvantaged or constrained by the effects of asthma symptoms. Better management of asthma results in fewer work days lost for adults, and reduced school absenteeism for children. It is believed that along with hospital admissions from asthma, half to two thirds of asthma deaths should be preventable (Bauman 1998). If we can improve adherence and continue to manage asthma more successfully, we can reduce the human cost of asthma and the costs to the health care system of emergency and hospital admissions or other crisis interventions.

## Section II - Influences on Adherence

By now, it should be clear that there are many factors that influence a patient's level of adherence. Adherence should always be evaluated within a context, taking into account the behavioural and environmental factors which impact on adherence.

The literature shows evidence for the following factors affecting adherence:

### Regimen on Complexity

Put simply:

- The more medications prescribed, the less likely they are to be taken. One study measuring compliance with inhaled medication in asthma showed that as medication dosing became more frequent the adherence decreased from 71% twice a day to 18% four times a day (Coutts, Gibson & Paton 1994).
- The more frequent the dose, the less likely it is to be taken.
- The greater the interference with lifestyle, the less likely the patient is to adhere.

### Readability of Materials

The data about readability of information and instruction leaflets indicates that many are too difficult for patients to understand. This has obvious implications for adherence (Smith et al. 1998). It is important to be mindful of a patient's level of education, cultural background, and literacy skills when providing information.

Most people with asthma use their medication as prescribed when they are symptomatic, as there is an immediate connection between taking medication and the relief of symptoms. For the same reason, adherence with reliever medication tends to be greater than adherence with preventive medication. Once symptoms resolve, continued adherence becomes increasingly difficult for many people with asthma (National Asthma Campaign 1998).

### The Patient's Health Beliefs

People bring into the consultation their own beliefs and perceptions about the illness. A study found that exploring these beliefs about the illness and the benefits and barriers to taking medication and working with the patient to come up with some sort of solution, led to better patient outcomes (Janz & Becker 1984; Innui, Yourtee & Williamson 1976; Cockburn 1997).

There is some evidence that compliance decreases when the frequency of dose increases. There is, however, no convincing evidence of an important difference in compliance levels between one and twice daily dosing. Pular (1998) concluded that, '...compliance with the once-daily regimen was best, but...compliance with a twice-daily regimen was very similar and both are superior to doing three times a day'.

A number of studies describe marked differences between the beliefs of patients and doctors about diagnosis and treatment. The patient's so-called 'unorthodox' (i.e., different from the current bio-medical) beliefs may well be unvoiced in the course of an otherwise unremarkable consultation. It is thought that these may be significant predictors of non-adherence (Britten 1996).

### Attitudes to Medications

Communication and open-ended questioning are useful tools to discover a patient's attitudes to medications and medicine-taking, which will certainly influence their adherence to treatment. Sociological literature identifies the following attitudes to medications in many patients:

- the danger of becoming 'immune' over time
- the 'unnaturalness' of manufactured medicines
- the danger of addiction and dependence
- an 'anti-drug' attitude

(Royal Pharmaceutical Society 1997).

An Australian study suggested that in some circumstances, non-adherence can be seen as an active attempt by the patient to reduce medication use. This has been termed 'intelligent non-adherence' because of the process through which the patient is trying to do what the doctor does, which is to manage asthma with the lowest dose of drug possible (Toelle 1998).

Always provide an opportunity for patients to express any concerns about the medication. Unvoiced concerns about continued drug use are a prime reason for discontinuing appropriate self-management. Give a balanced explanation of the benefits/risks of the medications.

## The Quality of Interactions between Health Professionals and Patients

The quality of interactions between doctor and patient can have a major influence on health outcomes (Kaplan 1989; Toelle, Peat & Dunn 1998).

As stated, communication and partnership, combined with flexible, non-judgmental and pragmatic attitude, lead to improved patient outcomes in terms of adherence.

## Psychological Factors

There is an emerging field of research which has identified psychosocial factors as particularly important influences on adherence, and a risk factor for asthma death (Rea et al. 1986). Broadly defined, these factors could be psychiatric illness, drug abuse, intellectual handicap, denial of asthma severity or social isolation. Psychosocial factors were found to have contributed to the asthma episode in 86% of asthma deaths and 88% of cases of near-fatal asthma (Campbell et al. 1992). Diabetes literature supports the importance of psychosocial factors in adherence. There is evidence that having a supportive family is associated with better self-management in adolescence (Evans 1993). Adherence is also affected by the patient's physical or social vulnerability (for example, being old, belonging to an ethnic minority, suffering from a psychiatric illness) (Royal Pharmaceutical Society 1997).

International research has also identified elements which are not good predictors of adherence. There is a weak correlation between the following demographics and the way in which medication is taken:

- age
- sex
- socioeconomic status
- severity of disease
- disease-specific knowledge

(Royal Pharmaceutical Society 1997).

Nevertheless it is clear that these factors and issues or factors should still be taken into account when assessing a patient's adherence to treatment, or devising a management plan. For example, here are some thoughts about **the influence of a patient's age** on their capacity/willingness to adhere to treatment:

'...the best drug in the world is only as good as it is able to be correctly used. (Sawyer 1998)

Barriers to adherence by **children** are compounded by their dependence on parents (or carers) for the provision and often administration of their therapy. Communication with the parent or carer is important so that you can elicit their concept of asthma, which has a powerful effect on therapy and adherence. This concept will be influenced by the parent's own experience of asthma, and their experience with family members or friends. For children, the functional status of the family plays a major role in influencing adherence, for example, the number of children in the family, the number of parents administering medication, issues of time management.

'...there are still many issues of peer pressure for many children - avoiding the use of preventive medication at school can help to ease this barrier. There should be regular reviews to update children with asthma. It is important not only that the child has an age-appropriate delivery device, but as they get older that they can actually contribute to the decision about delivery devices used.'

(Robertson 1997)

Young people develop increasing independence during **adolescence** and want greater autonomy and control. They continue to require a variable level of supervision and support from parents. The growing influence of peers and the values they espouse has great significance during adolescence. For some young people, the presence of asthma and the requirement for regular medication acts as a barrier to participation in peer activities. For others, the importance of establishing a regular routine for medication has greater salience for adherence.

Young people can experience a conflict of priorities when it relates to asthma management, such as the need to be socially acceptable to peers versus the requirement to take regular medication. The influences on young people's behaviours may not be obvious. For example, some young women are too embarrassed to use their inhaler in front of boys because of its phallic shape (Morsch, Stewart & Roller 1996). Clearly, gaining an understanding of the young person's perspective, values and aspirations is a key goal for health professionals if they are to influence health promoting behaviours. While striving for the best health outcomes, health professionals should aim for pragmatism not perfection (Bowes 1997).

'Many young people with asthma are employed part-time in pubs or the entertainment area which exposes them to cigarette smoke in their work environment. Having a job is often more important to them than avoiding environments which can exacerbate their asthma.'

(Bowes 1997)

**Older people** also have many unique factors influencing their adherence. Some studies have indicated that 25-50% of particular groups of elderly patients do not, or cannot, take all their medications as prescribed (Shimp 1985). Older people are more susceptible to adverse reactions to medications, which discourage adherence (Williamson 1980). The issue of drug interactions can also increase the incidence of fear amongst the elderly about the amount of medication they take. Also, 20% of those over 85 years of age have poor vision. Other factors to take into account include: strength and motor coordination; cognition (the incidence of dementia is expected to go up vastly over the next 20 years); depression and isolation. Older people also tend to under-report their symptoms. The presence of other diseases (such as heart disease) makes asthma symptoms more difficult to identify (Yates 1997).

The following factors do not have the same level of concrete evidence from the literature as proven influences on adherence, but are still important considerations

## Social and Cultural Factors

One study found that people who had better family communication were more likely to follow advice; we all know that family support is important. There is some level of evidence from the psychiatric literature that by actively soliciting family support, people might be more likely to adhere (Zhang et al. 1994).

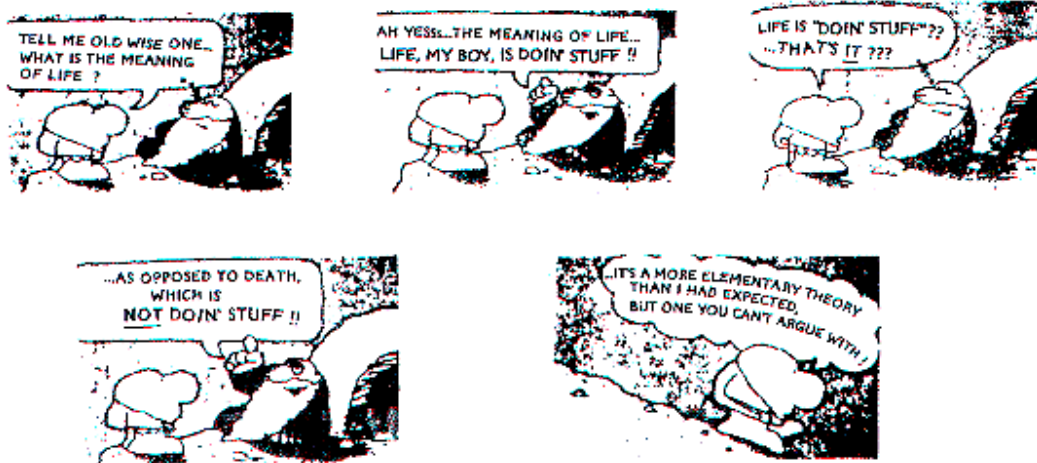
## Doctor/Patient Communication

Goldberg (1983) found that when doctors used strategies such as open-ended questions at the beginning of the consultation, showing empathy and warmth and following up on verbal cues, it resulted in more accurate diagnoses. Consultation styles do lead to more accurate detection and assessment of non-adherence (Cockburn 1997).

## Theories of Behaviour Change

Healthy behaviour can be seen as a means of achieving higher priorities, or it can be seen as a constraint.

Adherence is not a high priority for most patients. Most people are simply interested in getting on with what they want to do in life, and hopefully not having their asthma interfere with their ability to do that. One study of people with epilepsy (Conrad 1985) showed that patients' medication-taking behaviours were more influenced by events in their daily routine than by their doctors' advice. If poor adherence works for them, why should they change? The disruption to routine, or reduced spontaneity that comes with some treatment regimens may be seen as too great a cost for some patients, especially if the patient does not identify any real benefits from adherence.



Ziggy Cartoon about doin' stuff, ©Ziggy and Friends, Inc. distributed by Universal Press Syndicate. Reprinted with permission. All rights reserved.

### 'Doin' stuff

'The Ziggy Principle was formulated by Bob Kaplan (1994). Ziggy is an American cartoon character: to Ziggy the meaning of life is 'doing stuff'. For most people, the Ziggy Principle informs the way they feel about their lives: doing stuff, or our capacity to do things and behave, is more important than our medical 'health status'. For most of us, most of the time, health is a fairly low priority. We see it as a means to an end so we can do all the stuff that we want to be able to do. People are usually trained to optimise their life outcomes, and most people in the health field are focusing on trying to optimise health outcomes. It is worth keeping in mind that the two are not necessarily the same and that your goals may not match those of your patient.'

(Borland 1997)

Models of individual behaviour change in psychology tend to focus around what are known as expectancy value models, which an economist would call a cost benefit analysis. Basically, it is a cognitive appraisal by the patient - what's in it for me? - looking at the barriers of the costs, and comparing them with the perceived benefits. For example, in terms of taking medication, a child may perceive the benefit of earning the praise of her mother, but also be wary that her friends at school will laugh at her if she takes her medication, acting as a barrier.

Most models argue that our beliefs lead to our behaviour. Many health professionals also know that behaviour changes can also work on a patient's initially negative attitude: 'Just try it a couple of times, and see how it goes ...' We need to find a way to get patients to change their behaviour, by convincing them that the benefits of adherence outweigh the costs, and devising practical strategies so that the treatment plan fits in as neatly as possible with the patient's lifestyle and aspirations.

## Patient Attitudes

A qualitative study from Canada explored patients' experiences of asthma. It found that initially patients identified two key feelings: loss of control and fear. The process of overcoming these feelings and moving to

acceptance and having the asthma controlled, rather than being controlled by the asthma, came through knowledge, self awareness and experience, facilitated by a mentor (Snadden & Brown 1992).

## Personal Risk Management Strategies

There is some evidence that patients themselves attempt to analyse their positive and negative perceptions about the medicine and carry out their own cost-benefit analyses (Donovan 1992). This may then manifest as poor adherence.

## Section III - How to Improve Adherence

### Attitude

As we have stated throughout this guide, if you as a health professional are willing to modify your behaviour and role beyond the medical model towards a partnership approach to your relationship with your patient, this will positively affect the patient's adherence to treatment.

'... patients need to know less about the pathophysiology of their disease and more about integrating new demands into their daily routine ... (rather than to receive) ... standard presentations of medical facts and treatment rules which all ... asthmatics should know' (Mazucca 1982).

A commitment to partnership and a more equal relationship with your patient will foster communication and encourage the patient to take control of their self-management. This attitude should be based on a desire to understand the patient, their beliefs, their attitudes, their daily situation and schedule, and a non-judgmental attitude towards their non-adherence.

Treatment should be:

- Clinically effective
- Simple
- Convenient
- Inexpensive
- As free from side effects as possible.

(Meichenbaum & Turk 1987)

Focusing on the positive benefits of adherence, rather than the negative consequences of poor adherence, and devising practical strategies to address the impositions of treatment on the patient's life, will help to achieve a positive outcome. It is important to communicate to the patient that adherence will give them control, rather than asthma controlling them. If strategies or treatments have an unsatisfactory result, encourage the patient not to see it as a failure. Adverse reactions discourage adherence. Your attitude will help the patient to regard such incidents as learning experiences, rather than evidence that it's all too hard.

### Approach

'In the past, the usual approach when discovering non-compliance is to attempt to persuade the patient of the error of their thinking and to try and communicate the intentions of the prescription and the importance of sticking to the regimen. Research strongly suggests that this approach has been of limited value' (Royal Pharmaceutical Society 1997).

We now know that the best approach when faced with non-adherence is to work with the patient towards a relationship based on knowledge and understanding, in which the patient's individual barriers can be discussed and addressed in an open, non-judgmental way that normalises non-adherence. As a health professional you know the medical and scientific reasons why your patient should adhere, but without communication, it is not possible to understand what leads your patient to adhere poorly.

Adherence can be promoted, identified and monitored by a collaborative approach to patient care by the asthma management team. Consider the strengths of the various members.

**Pharmacists** are in a unique 'front-line' position to assess and monitor a patient/client's adherence. Indeed the Australian Pharmaceutical Formulary states that 'the pharmacist must ensure as far as possible that the patient receives the required therapeutic effect of the drug'.

The pharmacist is an easily accessible and no-cost source of advice for the asthma patient. The pharmacist is likely to see patients on long-term treatment programs more regularly than their GP, and as we know, adherence decreases over time. Pharmacists can take these encounters as an opportunity to check or reinforce the patient's correct use of medications, provide education or advice, reinforce or clarify elements of the patient's management plan. If pharmacists see evidence of non-adherence or that the treatment plan seems unsuited to the patient they can refer them back to their GP for review.

**Asthma educators** are increasingly becoming valuable members of the asthma care team. Education is crucial to adherence, as well as to asthma management in general. More and more GPs are referring

patients to asthma educators, who have the time and specific knowledge and skills to ensure patients understand their condition and their treatment.

Dr Jill Cockburn offers the following recommendations for best practice in addressing the use of adherence:

- Use appropriate overall interviewing skills
- Explore the patient's beliefs, offer solutions to barriers
- Use strategies to increase patient recall
- Reduce complexity of regimen
- Tailor medication regimen to patient's situation
- Use reinforcers, reminders, cues and feedback
- Elicit family support
- Monitor patient over time

(Cockburn 1997)

The relationship between **specialists and GPs** has significantly changed over the past five years or so with both groups of practitioners now working together more effectively. For non-emergency cases requiring specialist attention, there can be issues such as long waiting lists. Recently, the approach taken has been for the GP to contact the specialist for advice, and then administer treatment within the general practice setting.

The NAC has been a driving force behind collaborative efforts in managing asthma and facilitating discussion between professional groups. The team approach to managing asthma more effectively is already happening with the result that health outcomes for people with asthma have improved (National Asthma Campaign 1998). Our latest challenge, to improve levels of adherence, will benefit from continued collaboration and alliances between health professionals involved in the asthma management team.

## Strategies

In the next section you'll find practical suggestions to help you implement the following strategies in your work with people with asthma.

- Develop open, communicative, non-judgmental relationships with patients
- Normalise poor adherence in dealings with your patient
- Adopt a partnership approach to asthma management with your patient
- Involve your patient in the planning process
- Simplify treatment where possible, and strive to tailor treatment plans to your patient's preferences, needs and capabilities
- Ensure that your patient understands their asthma and treatment
- Collaborate with other health professionals to improve patient outcomes
- Aim to build a partnership with patients for ongoing care
- Encourage regular reviews and ongoing monitoring of adherence levels
- Develop systems (such as reminders) to prompt patients on long-term treatment programs.

## Practical Suggestions

### Use appropriate information-gathering skills

It is possible to facilitate better communication with your patients by:

- using skills such as open-ended questions at the beginning of the consultation
- avoiding questions that elicit a yes/no response or that are judgmental in their tone
- showing empathy and warmth and following up on the patient's verbal clues.



Such communication strategies will make it easier to assess possible non-adherence, and make it easier for the patient to discuss their individual issues and barriers to good adherence.

## **Facilitate open discussions with your patient about adherence**

Your attitude and your manner will help your patient to be honest and realistic when you are discussing adherence to different treatments for asthma. It is important to be non-judgmental and to normalise poor adherence (remember, around 50% of patients don't adhere to prescribed therapy).

Ask questions that will elicit information about the patient's health beliefs, their attitude to their diagnosis and their willingness to make behaviour changes in order to better manage their asthma (see tips).

## **Use reminders**

A number of prompts and reminders have been demonstrated to improve adherence:

- telephone or postcard reminders
- individualised reminder charts
- diaries
- engaging family members and carers to provide reminders

## **Facilitate recall**

Health practitioners who use strategies such as repetition, giving specific advice, using written information, increase the recall of the patient. Knowledge of what to do is a prerequisite of adherence (Royal Pharmaceutical Society 1997).

Improve patient recall by providing written education material and a written record of medication names and doses.

## **Explain likely side-effects**

One of the quickest ways to engender non-compliance with therapy is for a patient to experience side-effects about which they have not been forewarned. Discuss possible side-effects and suggest ways these can be minimised.

Factors that improve partnership:

- Body language
- Enquiring about patient's concerns
- Reassuring the patient
- Addressing immediate concerns of the family
- Interactive exchange
- Therapeutic regimen to fit patient's schedule
- Praise for correct management
- Eliciting patient's own goals
- Reviewing the long-term plan
- Helping the patient in advance

(Clark et al. 1995)

Always provide an opportunity for patients to express any concerns about the medication. Unvoiced concerns about continued drug use are a prime reason for discontinuing appropriate self-management. Give a balanced explanation of the benefits/risks of the medications.

## **Involve the patient in the planning process**

One way to encourage regular review is to focus on short-term goals while highlighting the long-term objectives. Short-term goals set around patient priorities such as sporting participation or fewer days off

school or work are more likely to be successful than physiological goals such as peak flow. Setting end points, where patients know that reaching a certain goal will result in changes to medication, may encourage regular review (Sawyer 1998).

With older patients, remember that the number of medications prescribed increases with age. The more medications used, the less likely people are to adhere. As the numbers of medications prescribed increases with age, the elderly are particularly at risk (Australian Institute of Health and Welfare 1994). If possible, not more than 3-4 drugs should be given each day.

- Explain to the patient (or their parent/carer) that you are trying to make them more competent to manage the disease themselves - and that your role is as an adviser.
- Don't try to instruct patients in all aspects of asthma at one consultation - build their knowledge base over consecutive visits.
- Simplify medication regimens where possible.
- Use once or twice daily dosing whenever possible.
- Make sure the patient's Asthma Management Plan is in a written form that they can easily understand.
- Encourage patients to see you even when they're feeling well - adherence needs to be continually monitored over time.
- Emphasising disease severity will not necessarily make patients adhere better; helping them realise just how good they might feel is more likely to be successful.

## Frequently Asked Questions About Adherence

### **1. I know that gaining a better understanding of my patients, and their beliefs and attitudes towards asthma and its treatment is meant to be important, but how do I do it and where do I find the time?**

While an individual discussion of these issues may appear to take more time, research shows that consultations that use the communication skills referred to in this guide can lead to better health outcomes, more satisfied patients and shorter consultations. More satisfied patients will be more likely to return for follow-up, more likely to be honest and open in discussions, and less likely to require emergency management of asthma.

### **2. What's the most reliable way of finding out if my patients/ clients are adhering?**

The accurate measurement of adherence is difficult. Although electronic devices, for use with medications and peak flow meters, do exist these are unlikely to be of practical use in the clinical setting. However studies show that patient admission of poor adherence is believable. Efforts to normalise *poor* adherence, the use of open ended questions and an information rich questioning style are more likely to allow people to admit less than ideal adherence. This can then be a starting point for identifying barriers and developing strategies to improve adherence.

### **3. How much adherence is enough? Is absolute adherence necessary?**

We don't really know the answer to these questions. Our decisions about what treatment to prescribe are guided by the results from clinical trials. These trials provide us with information on health outcomes for a particular dose of medication. We aim for 100% adherence with the treatment regimen but we don't really know whether there is a meaningful clinical difference between patients who are 100%, 95%, 90%, 85% and 80% adherent to the regimen. We do know that adherence is variable, and often poor, and the more we can do to enhance adherence the closer we should move towards the health outcomes demonstrated through clinical trials.

### **4. Surely treatment regimens allow for low adherence. Could improved adherence create problems?**

The objective studies of adherence have all been exactly that, research studies. These show regularly that adherence is only about 50%. Therefore, participating in a clinical trial does not of itself result in good adherence, as was thought. Consistent with this knowledge, drug studies generally use a 'run-in' period where patients who are not adherent with monitoring can be identified and do not participate further. The clinical benefits of improving adherence far outweigh any possible adverse effects.

### **5. What is the most important thing I as a doctor / pharmacist / nurse / asthma educator can do?**

The most important thing that you can do is to work in partnership with your patient. This means that adherence is an issue for both of you. Sharing the responsibility for good management and asking yourself, 'how can I best help my patient to follow their treatment plan' is an important step. Ask the patient what aspects of their management concern them. These concerns may be personal or they may relate to you. Communicating and working together is the most important thing you can do.

### **6. Which is more important, explaining the medication or management plan better or actually simplifying the regimen?**

Simplifying the regimen is likely to be more important in addressing adherence in the first instance. There is not much point to lengthy explanations about medications or plans if the regimen is too complex to deal with. The more frequent the dosing the less likely the drug will be taken. Also, different delivery devices can lead to confusion regarding best aerosol technique and result in poor drug delivery. Simplifying the regimen is an important first step which can then be built on.

**7. Why would people with asthma be more inclined to adhere if they are a partner in deciding how to manage their asthma?**

As a partner in the clinical situation the patient is able to communicate their views, feelings, concerns and take an active role in the outcome of the consultation. The input from the patient is used to guide the treatment regimen and so they themselves have crafted a plan or course of action for their own use. Ownership and control are important factors in ensuring the success of a self-management plan.

**8. In theory I believe in self-management and shared responsibility but many of my patients couldn't cope with it. What's the alternative?**

Some patients may appear to cope better with a more authoritarian style of communication. An authoritarian style may also appear easier for you the health professional, especially if this is your usual practice. However, this style of communication is not helpful in identifying patients with poor adherence. An interactive and open communicative style should be our goal, given that this is more likely to elicit poor adherence, the starting point for improved asthma outcomes.

**9. How do I get through to the person with asthma just how important adherence is for them?**

Encourage your patient to conduct their own clinical trial. Find out what health outcomes they would like to achieve and work out a course to accomplish these. It may just be that the patient has dropped themselves back to a level of adherence which provides them with the asthma control that they desire.

**10. What skills do I need to develop? What do I need to know and understand?**

Communication skills mentioned throughout this guide are likely to be of most benefit to enhancing adherence. Being able to get patients to feel comfortable enough to express their attitudes, beliefs and concerns about asthma is likely to be an important starting point for dealing with adherence.

**11. How do I manage this notion of an asthma care team? How important is it really?**

The asthma care team is an important concept in the management of asthma. Members of the asthma care team include the doctor, pharmacist, patient, nurse and asthma educator. Much greater results can be achieved by a coordinated approach and teamwork. Patients who are supported by the asthma care team have a number of resources on which to draw to assist them to manage their asthma and to achieve the control they desire. By working together we can assist each other and the patient to minimise the impact of asthma.

## Using Adherence Tools

There are various tools available to help you assess adherence. The following questionnaire is an example of structured means through which to better understand the person with asthma and to provide insights upon which to develop a manageable adherence regimen.

The Alfred's Asthma Education Profile Questionnaire (AEPQ) is designed in two parts. The first part explores the health beliefs (Maiman & Becker 1974) of the person with asthma and provides a framework for an educational context. It also provides an opportunity for the educator to address concerns and misconceptions the person may have about asthma.

The second section allows identification of specific gaps in knowledge and skills necessary for effective self-management. This allows the educator to tailor the information to the needs of the individual, '...the information patients need is that which enables them to understand how to deal with their specific management problems' (Clark & Nothwehr 1997).

# Administration Guidelines

The AEPQ takes 15 to 20 minutes to complete.

## PART 1

- The issues raised in this section are best addressed at the time of administering the questionnaire<sup>1</sup>.

## PART 2

- Do not attempt to undertake any knowledge and skills education while administering the questionnaire.
- Any questions to which the patient's response is NO or UNSURE indicates a need for education, except question numbers i)d and ii)h where a YES response indicates a need for education.
- If more than one area or topic needs to be covered then prioritise and note in history/discharge summary/interim action plan.
- The order of priority should be determined by the doctor/nurse/educator undertaking the advice or education program. However, as a rough guide you may wish to follow this order:
  - signs of worsening asthma
  - following an action plan / peak flow monitoring
  - Medications
  - medication technique and delivery devices
  - physiology
- The Behaviour Change Protocol uses an empowerment approach. It is designed to ascertain the patient's views of their own progress, using prompts to help them find their own answers to difficulties. It is as applicable to other chronic diseases as it is to asthma and the original was developed for diabetes care.
- You may find it impractical to use such tools in your everyday work. However, they do provide a useful guide for the types of questions to be asked and how discussion about asthma and adherence can be approached in an open manner.

1. A response guide forms part of The Alfred Inpatient Asthma Education Program from which the AEPQ is drawn.

# ASTHMA EDUCATION PROFILE QUESTIONNAIRE

## PART 1 – HEALTH BELIEFS

a) How do you feel about having asthma?

.....  
.....

b) What concerns do you have about your asthma?

.....  
.....

- |  | Yes                      | No                       | Unsure                   |
|--|--------------------------|--------------------------|--------------------------|
| c) Are you concerned about family members having/getting asthma?       | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Does asthma affect your lifestyle?                                  | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| e) Are you aware of any effective treatments for asthma?               | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| f) Do you think you can do anything to improve control of your asthma? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

## PART 2 – ASTHMA SELF-MANAGEMENT

### i) Causes of Asthma

- |  |                          |                          |                          |
|--|--------------------------|--------------------------|--------------------------|
| a) Do you know what is happening in your airways?          | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| b) Do you know what things cause your asthma to get worse? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| c) Do you know how to avoid things that make your worse?   | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| d) Do you smoke?   | <input type="checkbox"/> | <input type="checkbox"/> |                          |

### ii) Medications

a) Which relievers do you use? (Please circle)

Ventolin / Atrovent / Bricanyl / Asmol  
Respolin / Airomir / Theodur / Neulin

with spacer / without spacer

b) Which preventer do you use? (Please circle) Yes    No    Unsure

None / Becotide / Becloforte / Pulmicort  
Flixotide / Intal (Forte) / Tilade / Respocort / Prednisolone

with spacer / without spacer

c) Which symptom controller do you use?

Serevent / Oxis / Foradile

with spacer / without spacer

d) Do you take any other medications for your asthma?  
If so, what?

.....  
.....

e) Do you know what each of your medications does?        

f) How many times, each day, do you usually need \_\_\_\_\_  
to use your reliever?

g) How many times, each day, do you usually use \_\_\_\_\_  
your preventer?

h) Do you ever forget to take your preventer?        

i) How many times a week would you forget to take \_\_\_\_\_  
your preventer?

**iii) Devices / Techniques**

a) Do you know how to use your inhalers properly?           
*(Ask for demonstration)*

b) Do you rinse your mouth after your preventer?        

**iv) Monitoring Asthma**

a) Do you know how to control your asthma by looking for:

(i) low peak flow reading?        

(ii) symptoms of worsening asthma?        

b) Do you have a peak flow meter?    

c) When do you use your peak flow meter?

.....

		Yes	No	Unsure
<b>v)</b>	<b>Worsening Asthma / Action Plan</b>			
a)	Do you know when your asthma is getting worse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
b)	Do you have a written plan from your doctor?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
c)	Are you confident you can usually manage your asthma symptoms?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
d)	Are you confident you can prevent your asthma symptoms from becoming severe?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
e)	Are you confident you know what to do when your asthma becomes worse?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

2. The questionnaire is based on information from The Health Belief Model as described in Clark, N.M., Gotsch, P.H. & Rosenstock, I.P. 1993, *Patient, Professional and Public Education on Behavioural Aspects of Asthma: A Review of Strategies for Change and Needed Research*, 30(4), pp. 241-55; Kohber, C.I., Davies, S.L. & Bailey, W.C. 1994, How to implement an asthma education program, *Clinics in Chest Med*, 16(4), pp. 557-65; Gibson, P.C. & Wilson, A.J. 1996, The use of continuous quality improvement methods to implement practice guidelines in asthma, *J Qual Clin Practice*, 16, pp. 87-102.

**BEHAVIOUR CHANGE PROTOCOL**

This is a series of questions to help patients commit to a behaviour change plan that will lead to improved adherence<sup>3</sup>.

**1. What part of living with asthma is most difficult for you?**

*Focuses on patient's concerns, which may differ from professional's concerns*

.....  
.....  
.....  
.....  
.....

**2. How does (the situation described above) make you feel?**

*Allows depth of feeling to be expressed*

.....  
.....  
.....  
.....  
.....

**3. How would this situation have to change for you to feel better about it?**

*Allows patient to identify how the situation could be and how they would feel if it were improved*

.....  
.....  
.....  
.....  
.....

**4. Are you willing to take action to improve the situation for yourself?**

*Helps patient see how committed they are to changing situation*

.....  
.....  
.....  
.....  
.....

**5. What are some steps you could take to start this off?**

*Helps develop plan, note barriers and resources*

.....  
.....  
.....  
.....  
.....

**6. Is there one thing that you will do when you leave here to improve things for yourself?**

*Focuses on what patient can do to start the process - write if possible*

.....  
.....  
.....  
.....  
.....

3. Adapted from the model provided in Anderson, R.M., et al. 1991, Learning to empower patients: results of a professional education program for diabetes educators, Diabetes Care, 14(7), pp. 584-7, and used as a tool in health professional training conducted by the Lung Health Promotion Course at the Alfred Hospital in Melbourne.



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## Tips

Adherence is a major factor in successful asthma management.

### It will be improved by:

- ensuring your patient understands their asthma and treatment
- simplifying medication
- adopting a 'partnership approach' with your patient, and
- teamwork from all health professionals involved

### At each consultation consider

- Does your patient have a problem with their asthma?
- Is lack of adherence to a management regimen a possibility?
  - Is it possible they don't understand what is required?
  - Do they have skills for remembering?
  - Do they think it's worthwhile to adhere?
  - What are the implications for them of non-adherence?

### These questions may help you create a dialogue and provide a basis for improved adherence. At Diagnosis:

- How important is your health to you when you consider everything else that is going on in your life?
- Do you agree with my diagnosis of asthma? Are there any questions/concerns you have about the diagnosis?
- How serious do you feel your asthma is?
- How do you feel about the medications prescribed?
- Are you concerned about possible side-effects?
- Do you think this treatment plan will work? What potential difficulties might there be?
- On a scale of 1 (least effective) to 10 (most effective), what would you rate yourself as being able to do of the things we have discussed?
- Is it clear to you what we need to do to help manage your asthma?

### For Review

- How is the treatment plan going? Let's go over it. Are you experiencing any difficulties?
- How often do you forget your medications?
- Are there times when you are more likely to forget your medications?
- How do you usually remember? What can we do to help you to remember?