

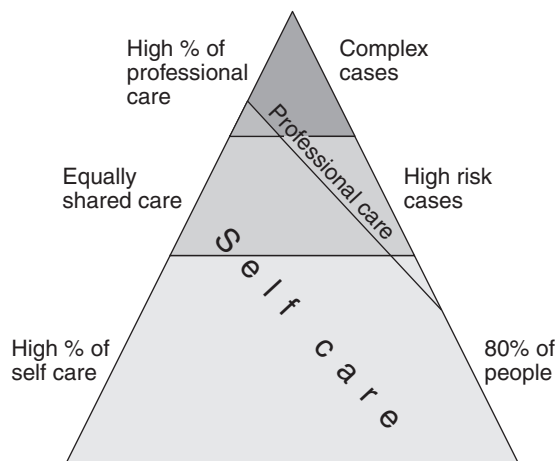
## What we know about the practice and impact of self care

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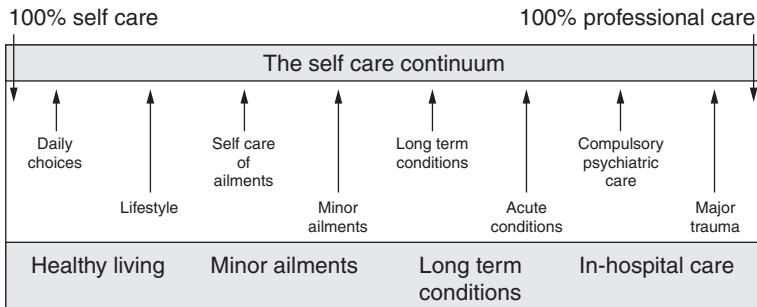
*This chapter describes the scope of self care in the UK and considers what we know from recent work in the field about its impact.*

Self care is the basic level of health care in any society.<sup>1</sup> In the UK, self care comprises an estimated 80% of all care episodes. Figure 2.1 shows the relationship of self care to professional care, and demonstrates how professionals and the public are co-producers of care.

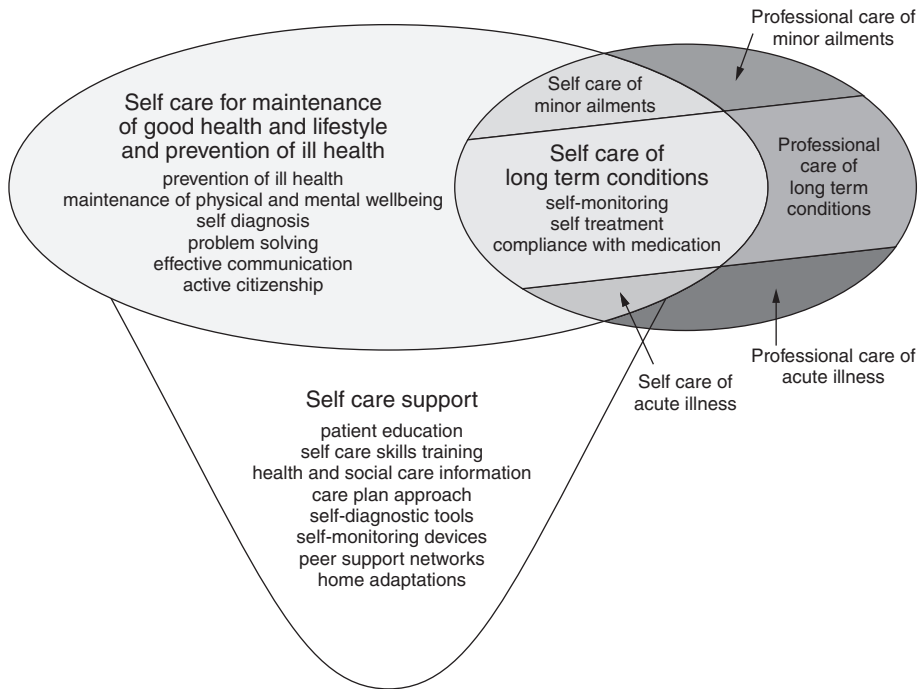
Self care is a continuum, starting from the individual responsibility people take in making daily choices about their lifestyle, and risk taking. This may be in their work, travel and hobbies, and other aspects of their everyday lives. Next along the continuum, Figure 2.2 shows the self care of ailments without and with assistance from health professionals such as pharmacists, GPs or practice nurses. Shared care follows – by health professionals together with their patients, as individuals cope with long term health conditions and acute health problems. Ultimately on the right hand of the continuum there is 100% professional care with little or no opportunity for self care in the immediate episode, e.g. complex co-morbidities, compulsory psychiatric care or major trauma or illness – until the start of recovery when self care can emerge again.



**Figure 2.1:** The health care pyramid.



**Figure 2.2:** The self care continuum.



**Figure 2.3:** Self care support for maintenance of good health and lifestyle, and prevention and care of ill health (courtesy of Ayesha Dost, Department of Health).

Figure 2.3 maps the various approaches to self care, from the achievement and maintenance of good health and a healthy lifestyle to the prevention of ill health and minimising symptoms from minor illness. The figure also introduces the inter-relationship between the promotion of health in the community through social care, outside the primary care setting.

## Components of self care

The aims of promoting self care among your patients or the local population are to encourage individual people to:

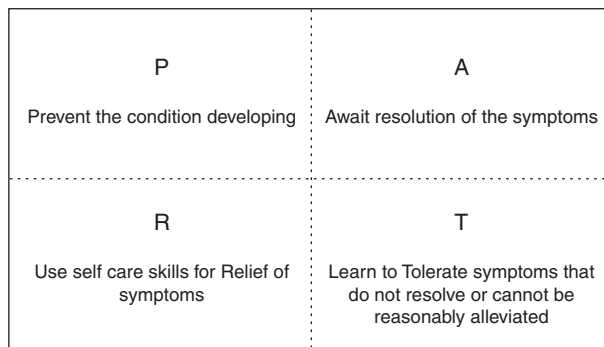
**P:** Prevent the condition developing

**A:** Await resolution of the symptoms

**R:** use self care skills for **R**elief of symptoms

**T:** learn to **T**olerate symptoms that do not resolve or cannot be reasonably alleviated.<sup>1</sup>

The size of each PART quadrant in Figure 2.4 will depend on the specific level and range of self care skills for a particular condition.



**Figure 2.4:** The PART model to illustrate pathways for self care.

Enhance the level of self care skills of individuals and self care support provided by the NHS by considering each component. Push the boundaries of self care to the maximum that is safe for your patients or the general public, and affordable in terms of resources such as time and capacity of primary health care professionals.

Some self care support approaches will focus on one of the quadrants. Others may have more than one component in the total intervention. The case study in Box 2.1 combines **P**revention of worsening asthma using preventive therapy more effectively and by smoking cessation, with **R**elief through better use of medication.

### **Box 2.1:** Case study: proactive self care support for people with asthma

Fifty practices in 25 PCTs are participating in 'Asthma Care', a proactive telephone outreach service to support self care. A nurse contacts individual patients in a series of regular calls to discuss their asthma and related issues. Smoking cessation advice is also given, as is explanation of the importance of preventer therapy, and where reliever therapy fits in. Overall, around one-third of patients did not have an action plan for their asthma. Patients were referred to their asthma nurse or GP where needed. An evaluation was conducted with 150 patients who had completed the programme and reported: better understanding

of their asthma (86%); improvement in their asthma (69%); better compliance with preventer medicine (39%); reduced amount of reliever medicine taken (40%). Patients felt they had time to discuss their questions and had confidence they could raise other issues.<sup>2</sup>

The case study reported in Box 2.2 describes **Tolerance** and **Awaiting** resolution as well as **Relief** of children's minor ailments. Involving the family and carers is important in promoting self care. Families have a strong influence on someone's use of health services and health seeking behaviour.<sup>3,4</sup>

**Box 2.2:** Case study: education and advice on children's minor ailments

Sure Start and four local pharmacies on an estate in Hull are collaborating to make greater use of pharmacies as health advice centres. The aim is to increase parent education on health issues in under-three year olds in an under-doctored area. Parents register with a local pharmacy for advice on children's minor health problems that they would otherwise have consulted the GP about. Simple information leaflets are distributed on the six ailments covered by the scheme: temperature/aches/pains; stuffy nose; colic; nappy rash; diarrhoea/sickness; teething; dry skin. Pharmacists can supply medicines free of charge for five of the six ailments. So far, no medicine has been supplied in 10–15% of cases. In roughly half of these, the pharmacist's view is that advice is sufficient and for the rest they think that referral for medical advice is necessary.<sup>2</sup>

Some conditions lend themselves to self care more than others. Problems such as back pain or sore throat are likely to get better anyway without any medical management or treatment. At the same time, people need information about the occasional serious aspect of their illness that requires medical attention. The 'red flags' in back pain, which if undetected and treated as an emergency can lead to permanent paralysis, or the very occasional sore throat that turns out to be a quinsy, require a safety net. Chapters 10 to 13 contain in-depth illustrative patient pathways covering back pain, asthma, cough and sore throat, and demonstrate how the four components of self care – prevention, await resolution, relieve symptoms and tolerance – apply to each condition. Look at Box 2.3 to think more about selecting appropriate types of self care support intervention.

**Box 2.3:** Gaining maximum impact from self care support intervention

A review of qualitative research on self care concluded that:<sup>5</sup>

a number of factors need to be considered when devising health care interventions for managing demand better. These include an assessment of the meaning of the disease to the person so that self care information can be designed in a way that fits people's prior beliefs and lifestyles. Timing and

the stage in a person's illness career are also important factors to consider when designing effective self care support interventions. Social interaction and the impact of significant others may affect whether or not a self care regime is followed, and autonomy and control are also relevant to designing acceptable self care strategies.

There are many innovative practical examples of self care support across all health settings. In a recent review no examples of a whole systems approach to self care across a health economy were found.<sup>2</sup>

## Educational interventions

People are capable of making informed choices and undertaking self care all along the continuum of Figure 2.2 from their increased understanding and motivation gained by educational interventions. A review of medical self care interventions concluded that:<sup>5</sup>

education in self care decision making and practices can produce significant effects in terms of health care utilisation and cost reductions.

It seems more worthwhile to focus educational campaigns on targeted individuals who have reason to benefit from self care. The consensus among health education researchers seems to be that behaviour change is unlikely to result from mass communication campaigns alone.<sup>6</sup> One evaluation of a cold/flu self care public education campaign, for example, resulted in no changes in people's beliefs, attitudes, acquisition of new health practices or self-reported visits to the doctor.<sup>6</sup>

The successful educational intervention may be just a simple explanation, targeted at the right person at an opportune time. In one study concerning children with earache, a brief explanation by the doctor to the parent about the inadvisability of using antibiotics resulted in 50% decrease in antibiotic use.<sup>7</sup> Hopefully that learning would continue for further episodes, resulting in fewer future consultations with a doctor for earache.

Poor patient understanding about their disease is believed to impede appropriate self care. Finding the right educational interventions that will have a long term impact on enabling self care and improving health outcomes in chronic disease is difficult. Any educational initiatives need to be designed with an awareness of the complexity of people's social and cultural experiences and attitudes typical of their community.<sup>8,9</sup> When considering the content or delivery of any intervention, remember who the target audience is and what specific barriers there may be to it being effective.<sup>10</sup>

Consider how to match the type of educational intervention to a particular person to optimise its impact.<sup>11</sup> Your information could be in the form of a book or leaflet, audiotape, interactive online resource, quiz, self-assessment checklist, poster, video, digital patient story or peer with similar condition. Ensure that the person you are trying to educate with such information materials really does have the disease it relates to and has not been misdiagnosed or is assuming that they have a condition

they have not got. That is difficult when information or education is simply made available for members of the general public or patients in general – but the material should be explicit and clear.

Use educational interventions that include specific information about inappropriate and harmful treatments too, and symptoms that could generate mistreatment – not just the simple guidance you hope to deliver about straightforward self care. It is easy to assume that people have basic knowledge which in reality they do not possess and that could undermine their ability to self care.<sup>12</sup>

Educational interventions are more likely to be cost effective if targeted at ‘high risk’ patients. For health education targeted at frequent users of health services, with conditions such as high blood pressure, diabetes, heart disease, back pain, it was found that slightly fewer consultations were recorded with a doctor in the subsequent six-month period combined with a little improvement in their health risk scores.<sup>13</sup> Another educational intervention involving people with Parkinson’s disease resulted in fewer visits to the doctor and fewer symptoms.<sup>14</sup>

Just as with the Expert Patients Programme (EPP) in England (*see* p. 106), another study of a self management education programme (EPP) has reported a reduction in pain and use of health services for people with chronic arthritis.<sup>15,16</sup>

Experience with self care health books is mixed. One American study considered the effects of distributing a series of seven self care brochures with home remedies and guidance on the appropriate use of health services for a common cold, sore throat, headache, fever, ‘flu, earache and back care.<sup>17</sup> The majority of recipients ‘liked or strongly liked’ the information and most kept the brochures at home. Health service use was unaffected and the researchers concluded that ‘educational programmes are more effective in raising awareness than in changing behaviour during the initial stages of an intervention’. It is likely that to achieve a reduction in use of health services requires:

ongoing and repetitive educational messages . . .

patients who feel more responsible for self care of simple health conditions who begin to consider taking a more active role in health improvement in other lifestyle related behaviours too.<sup>17</sup>

In another study nearly half of the 1967 patients in one practice who were given a self care book had consulted it. Those with health problems were more likely to have looked at it. Of those who had looked at the book, 60% reported that the book made them more likely to deal with a problem themselves, and 40% replied that they were less likely to consult the practice. However, the study found that there were *no* differences in consultation rates between those who had, or had not read the book they had received, or between those who received the book or others who had not had a copy of the self care book.<sup>18</sup>

Box 2.4 describes a selection of other educational programmes and their likely benefits.

**Box 2.4:** Examples of educational interventions linked to promotion of self care

- Effects of educational and psychosocial interventions for adolescents with diabetes mellitus: these had small to medium beneficial effects on various diabetes-related outcomes.<sup>19</sup>
- A whole systems approach to self management which included a self care guidebook for people with inflammatory bowel disease + physicians trained in patient-centred care + negotiated written self management plan. This trial resulted in fewer hospital visits without change in the number of primary care visits, fewer symptom relapses, and most patients liked the new system.<sup>20</sup>
- Information leaflets from voluntary groups or charitable organisations can enable people to take care of themselves. For example, the Arthritis and Rheumatism Council issues practical advice on management of rheumatic disease, including a handout on knee pain self management which stresses the importance of type and duration of exercise.<sup>21</sup>
- A study involving people with hypothyroidism showed:
  - brief intervention with an educational booklet has no influence on thyroxine adherence or health in patients with primary hypothyroidism. These findings do not support the routine distribution of health educational materials to improve medication adherence.<sup>22</sup>
- Intergenerational projects whereby older people support and challenge youngsters can improve older people's self worth, and thus health. Active ageing is the focus of the charitable organisation, the Beth Johnson Foundation.<sup>23</sup>
- Self help promotion clinics are another type of intervention that aim to empower people to improve their health and wellbeing. One study of a self help mental health clinic found that the combination of self help materials and individually tailored programmes of self help by a therapist allowed patients to self care, and limited the face-to-face therapist input of traditional services.<sup>24</sup>

Other examples are given in a self care compendium of practical examples.<sup>2</sup>

For every research study with positive findings there are probably many more that are unpublished as they have no positive findings. Consider too how long the participants in any study were followed up, and whether the impact of any educational intervention lasted for more than a few months.

It appears it is not sufficient to simply distribute educational materials. You also need to engage with the recipients to generate more impact on their behaviour from the intervention; or share decision making to enable individuals to help themselves.<sup>25</sup> A review of self help books available for depression illustrated the importance of engaging patients, maybe in cognitive behavioural therapy over time, running alongside their reading of the book.<sup>26</sup> You need to consider the costs incurred by such health professional support in enabling self care.

An intensive educational intervention given to people with asthma to encourage self management of their medication resulted in fewer consultations, days off work and courses of antibiotics. There were better quality of life scores with good adherence to agreed self management plans. But this was an intensive and therefore costly programme involving participants learning about lung anatomy and physiology, asthma and its causes, the effect and purpose of medication and the principles of self management, from specially trained nurses. They also received physio-therapeutic counselling.<sup>27</sup>

The *Joining Up Self Care* initiative in Erewash PCT has several strands, enabling people to take steps towards self care. As well as valuable information, an individual can use an aid to self assess their risks of heart disease based on their lifestyle and family history. They can obtain a lifestyle pack that matches their self-assessed level of risk from a local pharmacy or by making a free telephone call.<sup>28</sup>

There are a number of other very useful structured education programmes for people with diabetes. In the DAFNE (Dose Adjustment For Normal Eating) programme, participants with type 1 diabetes learn how to adjust their insulin dose to suit their choice of food.<sup>29</sup> With DESMOND (Diabetes Education and Self Management for Ongoing and Newly Diagnosed), participants with type 2 diabetes identify their own health risks and set their own specific behavioural goals.<sup>30,31</sup>

## Self care guides

In future, people's individual electronic health records should be linked with self care information and self care plans. The public already has access to national resources available for self care such as the NHS Direct range of services including the NHS Direct Healthcare Guide, NHS Interactive on digital TV, NHS Direct Online and algorithms (see page 94) or the self care booklet produced by the Developing Patient Partnerships (DPP).<sup>32-34</sup> The internet site BestTreatments developed in association with NHS Direct is based on *Clinical Evidence* and has resources for patients, as well as health professionals.<sup>35,36</sup> Similarly, *Prodigy* contains information sheets that can be printed off for individual patients.<sup>37</sup>

The example in Box 2.5 is of a guidebook for promoting patient participation in the care of ulcerative colitis.

### **Box 2.5:** Features of a successful self help guidebook

Patients with ulcerative colitis were involved throughout the process of developing a guidebook on the condition. Information was designed to empower patients and allow them to participate in making informed choices about their medical and surgical care. Patients wanted the content to: be positive about life with a chronic disease, explain the rationale behind treatment, give facts and figures about likely outcomes, and be updatable.<sup>38,39</sup>

## Self care of long term conditions

People report that self management of their long term condition puts them in control of their lives. An individual's involvement in self management is likely to fluctuate over time depending on how much time and importance they give to it.<sup>40</sup> Self management skills training in the early stages of a condition should help to prevent the onset of complications and further disability.<sup>41</sup>

Elements of self management support for people with long term conditions include:

- patient education
- patient psychosocial support
- self management assessment
- self management resources
- collaborative decision making
- guidelines available to patients.

Most NHS trusts have tried various forms of self care support for people with long term health conditions. These might be in the form of outreach support for conditions like asthma, educational programmes such as for diabetes or preventing falls, promotion of healthy lifestyles, for example through walking or by forming self care support networks. Some PCTs produce their own local health magazines. An effective approach to the care of people with long term conditions requires a system that works across the various settings of health and social care as an integrated system.

There is interest in the UK in the Kaiser Permanente approach from the US.<sup>42</sup> The Kaiser programme encourages self management by patients through lifelong learning. Patients are encouraged to take more responsibility for their own health. Kaiser provides patient education material on its website ([www.kaiserpermanente.org](http://www.kaiserpermanente.org)) for patients to access. Patients are educated in hospital to take care of their own health after discharge.

UK Pfizer Health Solutions helps people with long term conditions to become more active in taking care of their own health. The company works with NHS commissioning bodies to provide tailored services to meet the needs of local populations, drawing on experience from the US. A review of the US health system concluded that:

case and disease management programmes in which support for self management is a central feature should be developed in every PCT.<sup>43</sup>

NHS policy documents on care of people with long term conditions have emphasised the contribution of self care support. The long term conditions National Service Framework (NSF) aims to transform the way that health and social care services support people to live with long term neurological conditions.<sup>44</sup> The NSF features supporting self care around the needs and choices of individuals including health promotion.

Although enthusiasm is growing for self management programmes for people with long term conditions, there is conflicting information about their effectiveness and

what their essential components are. A meta-analysis that considered 780 published studies concluded that:

self management programmes for diabetes mellitus and hypertension probably produce clinically important benefits . . . osteoarthritis self management programmes do not appear to have clinically beneficial effects on pain or function.<sup>45</sup>

Self-monitoring of blood pressure may give a truer estimate of usual blood pressure than readings by a doctor in the surgery and may save time for health professionals. However, there is evidence that blood pressure measured by patients is inaccurate in as many as 50% of patients.<sup>46</sup> Another study enabled patients to take their own blood pressure, but at the general practice rather than in their homes, and initiate a consultation with their doctor or nurse if their blood pressure was repeatedly above target levels. This style of self-monitoring resulted in small but significant improvements of blood pressure at six months, which were not sustained after a year.<sup>47</sup> The researchers concluded that practice-based self-monitoring of blood pressure is feasible; the self-monitoring was well received by patients, their anxiety did not increase, and there was no appreciable additional cost.

Several studies have indicated that patient self management may improve the quality of oral anticoagulant therapy.<sup>48,49</sup> In one study, patients measured their international normalised ratio (INR) using the CoaguChek S every two weeks, or more frequently if required, for six months. They adjusted their own warfarin dose on the basis of their INR using the algorithm provided. The researchers concluded that:

in the majority of suitably trained patients, the quality of oral anticoagulant therapy achieved through self management is comparable to that obtained by self testing patients managed by a specialised hospital anticoagulation service.<sup>48</sup>

The second study over 12 months drew similar conclusions, and noted that patients with poor control before the study showed an improvement in control through self management.<sup>49</sup>

Experience of self management to date indicates that a whole systems approach is needed that improves information given to and shared with patients, improves access to services and encourages health professionals to adopt a more patient-centred approach.<sup>50</sup> Self care information on its own is of limited effectiveness. When this whole systems approach was adopted with guided self management of ulcerative colitis, patients preferred it to traditional outpatient care; there was earlier treatment of relapses and fewer follow-up visits to health services.<sup>51</sup> Open access to health services may fit better with patients' self management of their condition and everyday routines, roles and responsibilities.<sup>52</sup> Lay-led self management may be more effective than that which is professionally led (fitting with the ethos of the Expert Patients Programme<sup>15</sup>) when targeted at minority groups so that lay leaders may overcome cultural and language barriers. One such initiative had some success when lay tutors led a six week programme of three-hour sessions for Bangladeshi adults living in London, known to have diabetes, arthritis, respiratory or cardiovascular disease – although moderate uptake and attendance limited the benefits gained.<sup>53</sup>

## Using assistive technologies

Assistive technologies include a broad range of technologies such as home adaptations, as well as newer technologies such as email and text messaging. Some devices such as blood glucose monitors or nebulisers contribute to patients' self care. Email and text messaging are cheap and fast and are limited by patient preferences, as is use of the internet as a health resource.<sup>40,54</sup> Other devices range from sophisticated ones such as telemedical monitors to simple ones that are readily available in the high street, such as pedometers.<sup>55</sup>

## Self care support networks

The evidence for the benefits of lay-led self care networks, some of which may also be called 'self help groups', is still scant.<sup>56</sup> They are a potentially important method of delivering self care interventions for people with specific conditions and/or their carers. Many groups provide unstructured support with variable quality of self care materials. A review of the effectiveness of self help mutual aid groups in America found positive outcomes such as reduced psychiatric symptoms, less use of professional services, enhanced coping skills, increased life satisfaction and shorter hospital stays.<sup>57</sup> Box 2.6 relays some tips for anyone setting up a local self care support network.

**Box 2.6:** Encouraging local development of self care support networks

- Don't reinvent the wheel: get a starter pack from a group that already exists.
- Find a suitable meeting place and time.
- Publicise and run your first community meeting.
- Meeting tasks: be clear about the purpose – perhaps provision of emotional support, practical information, education, and advocacy. Set out basic guidelines such as about confidentiality. Define the membership, meeting format, people's roles and responsibilities, and the use of professionals. Exchange contact details.
- Start with a small project and work up to more difficult tasks.<sup>58</sup>

## Self care support provided by pharmacists

Chapter 6 contains many examples of self care support by pharmacists and their teams. Relatively simple interventions can make a big difference. A one-hour educational and medicines management visit by a community pharmacist which emphasised self care, medications and screening processes for complications, resulted in improved diabetic control in a study involving 80 patients. Teamwork between the pharmacist and health professionals in the general practice team was key.<sup>59</sup>

Some PCTs have tried out Pharmacy First ([www.erewash-pct.nhs.uk](http://www.erewash-pct.nhs.uk)). Box 2.2 described the collaboration between Sure Start and four pharmacies in Hull in making greater use of pharmacies as health advice centres.

## Can we afford to promote self care?

Some examples included here have demonstrated that supporting self care can result in tangible benefits to people's health and thus cost savings to the NHS and society in general, as healthier people can work harder and more effectively, for longer. While specific and reliable information about the cost effectiveness of the various types of self care is limited, the promotion of self care has been recognised as an important aspect of managing demand.<sup>60</sup> However, for any significant effect on demand in primary care, multifaceted approaches are required at all points, from avoidance of first contact with health services to possible referral to secondary care. The various components of an integrated self care support resource and the entire range of self care interventions must be considered when advising and supporting patients.<sup>61</sup>

The Wanless review suggested that in general for every £100 spent on encouraging self care, £150 worth of benefits can be expected in return.<sup>62</sup> In a systematic review of self help treatments for anxiety and depression in primary care, none of the eight studies included had data on long term clinical benefits or cost effectiveness.<sup>63</sup> A systematic review of the clinical and cost effectiveness of patient education models for adults with types 1 and 2 diabetes, for instance, found 24 studies of such education; but only two of these reported on the cost effectiveness of their educational intervention.<sup>64</sup> The trial of self-monitoring in hypertension found that self-monitoring did not cost significantly more than usual care.<sup>47</sup> A trial of a guidebook offering self help information plus a self help group meeting resulted in a 60% reduction in primary care consultations, and costs were reduced by £73 per year.<sup>65</sup> For the present, self care support may be developed and promoted in the hope that it will result in affordable benefits and be cost effective. Evidence suggests that

intervening at the community level is potentially more powerful or at least more cost effective than interventions at individual level<sup>66</sup>

unless the interventions are targeted at high risk individuals.

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