



Promoting Optimal Self Care

Consultation techniques
that improve quality of life
for patients and clinicians





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Foreword

'The NHS Improvement Plan' identified long term conditions as one of the three top priorities for the NHS in the period up to 2008. Long term conditions have become a priority because of the changing burden of disease and the increasing prevalence of conditions such as diabetes, asthma, arthritis and heart disease. People with long term conditions are more likely to see their GP, be admitted to hospital, and stay in hospital longer than people without long term conditions. They are also increasingly involved in managing their conditions with the support of the health care team.

The Government's approach to long term conditions has identified three levels of care. For the small number of people with the most complex needs, the aim is to offer *case management* in the form of community matrons. Case management is intended for patients with multiple conditions who are most likely to be admitted to hospital or become ill unless their needs are anticipated and addressed. People with less complex needs are offered *disease management* support through the primary care team and with specialist intervention when appropriate. Care for these people will often be provided by a specialist nurse or other professional trained in the condition concerned.

For the majority of people with long term conditions, *self care* has been shown to be effective in improving quality of life and promoting appropriate utilisation of services. The reasons are not hard to find. Most people who live with a medical condition over a period of time have a strong interest in developing the skills and knowledge to manage their condition in a way that enables them to participate fully in society. Not only this, but also the amount of time people are involved in caring for themselves is much greater than the time they are in contact with health care professionals.

It is for these reasons that supporting patients to self manage their conditions and to use health services when appropriate has been identified as an increasingly important element in the Government's long term conditions policy. Self care has been promoted through the Expert Patient Programme and a wide range of other local initiatives (Department of Health, 2005)*. It has also emerged as a core theme in the public consultation on the future of care outside hospitals undertaken during the autumn of 2005.

At a time when public expectations of the NHS are rising, and when people are increasingly involved as co-producers in other areas of their lives, there is every indication that self care is an idea whose time has come. Cottam and Leadbeater (2004)** go further to advocate 'communities of co-creation' as the way to radically redesign public services. By this they mean genuine partnerships between service users and providers to develop services that better meet the needs of the public.

One of the barriers to self care is scepticism and lack of interest among some health care professionals. Scepticism arises out of doubts on the strength of the evidence to support self care; lack of interest from the challenge of finding the time to promote self care in the face of competing pressures and demands. Healthcare professionals may also be unsure what they need to do to assist patients to self care.

This handbook provides many of the answers. It brings together the evidence base, offers practice examples and advice on what healthcare professionals can do, and makes a convincing case for self care to be at the heart of the new medical professionalism. Written by healthcare professionals for healthcare professionals, the handbook is a must read for all those seeking to improve the quality of care for people with long term conditions.

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*Department of Health (2005) Self care support: a compendium of practical examples across the whole system of health and social care

**Cottam H and Leadbeater C (2004) Health: co-creating services, The Design Council





Introduction

Self care works, produces excellent outcomes, improves clinicians' job satisfaction, reduces workload and saves money. Most importantly patients want it. Interested?

“If it feels like you are doing all the work you are not doing it right.”

Helping people to optimally self care involves using consultation skills that borrow heavily from the psychology literature. The techniques described here are relatively easy to pick up and can be used by all healthcare professionals. With practice, using these techniques has been shown to increase satisfaction in the consultation for both patients and clinicians.

“The role of a doctor is to add life to days, not days to life.”

We are unable to identify the origin of this quote, but perhaps it should more accurately read:

“The role of everyone is to add life to days, not days to life.”

This takes things further. It again implies the notion of quality of life as being of paramount importance but also says that people are responsible for improving their own quality of life. It is not the task of someone else to do it for them.

We hope this handbook will demonstrate that self care should be encouraged and facilitated for everyone who presents to a healthcare professional. The concept is of paramount importance for people with long term conditions, but can also be employed for people with self-limiting or medically curable disorders.

Numbers contained within parenthesis in the following style {} allude to the list of references on pages 71 to 73. The use of *italics* and/or **bold** text indicates either a reference to another section within this handbook or to give emphasis.

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Preface

In December 2004 the Department of Health invited bids for project funding to support work that would strengthen clinical engagement and leadership in the improvement of services for people with long term conditions. The Dorset and Somerset Health Community submitted a proposal entitled 'Clinical Leadership for Self Care' with the principal aims of enabling clinicians to promote self care effectively and developing local clinical champions for self care.

The funding bid was successful, and this publication is one of the main results.

Within Dorset and Somerset we are now in the process of cascading the learning included here, to ensure that people with long term conditions are encouraged and supported to self care, by all of the health professionals involved in their care.

The handbook has been written by healthcare professionals for healthcare professionals. It has been designed to be useful to all clinicians, and we appreciate that this will cover a vast range of skills and experience. For some new to this field it may be challenging, to those with more experience it may at times appear overly simplistic. Our hope is that all readers will learn something of value and enjoy it. During all phases of production, there has been consultation with a wide range of people who work in the health service, including policy makers. Most importantly, we have also consulted the people that we serve; people who live with long term conditions.

Those who have contributed to the development of the handbook are listed at Appendix 1, with our thanks. Particular thanks go to the principle authors of this book, Dr Stephen Tomkins, a GP within the South and East Dorset Primary Care Trust and Dr Alf Collins, Consultant in Pain Management at Taunton and Somerset NHS Trust. Their enthusiasm, knowledge and commitment to this project has been fundamental to its realisation.

The Steering Group would also like to thank the Department of Health and the Dorset and Somerset Strategic Health Authority for funding this project.

Jan Hull

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We are all busy people, so to save you time:

1. The chapters have been arranged so that important principles are presented as key points within shaded boxes such as this. These boxes could easily be read on their own in under one hour.
2. Chapters 1- 4 describe core skills. Chapter 5 and the appendices are extra reading for those who want more information.





SECTION 1

PRINCIPLES OF SELF CARE



1.1 What is self care?

KEY POINTS

- Self care is not the same as no care
- Outside hospitals or care homes, everyone self cares all of the time but not everyone self cares optimally
- Medical treatment and the way in which it is delivered can either support or erode the capacity to self care
- The Expert Patient Programme is not the only self care option. An understanding of the principles of self care is vital for everyone involved in supporting people with long term conditions

The overwhelming majority of people with a long term health problem want to maintain an independent and fruitful life. It follows that we should tailor our health and social care systems to support them in their independence.

But we don't always do that. People find themselves waiting for diagnostic tests or specialist opinion or they can feel lost in a system of care that was designed to help but can sometimes hinder their progress. Sometimes, people expect more of healthcare than it can deliver and they can, understandably, become frustrated and demoralised by 'the system'.

We argue that we should design all of our clinical interventions and care pathways with the explicit aim of facilitating self care. At every point in a care pathway, we should be asking ourselves:

“Am I doing as much as I can to help the person in front of me to be as independent as possible?”



Self care and self management

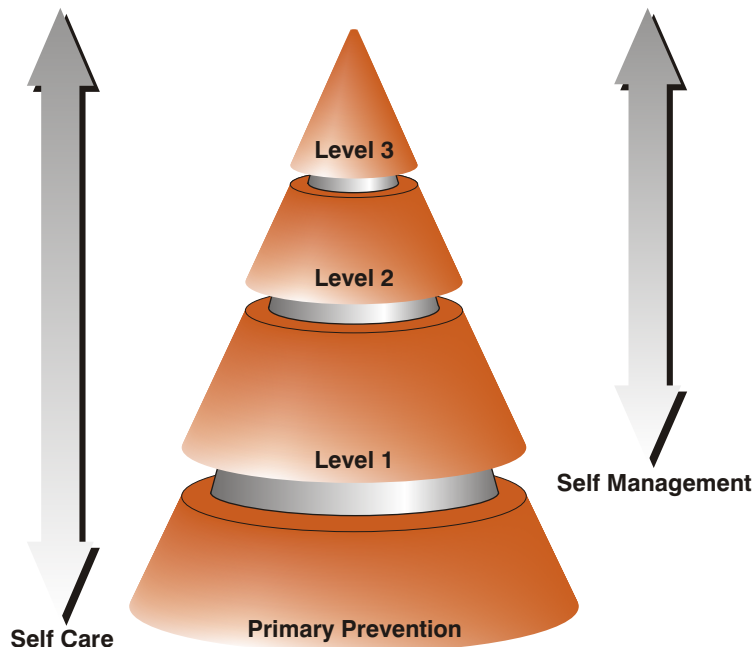
These terms have been used interchangeably in the past. The Department of Health defines self care as being:

“... about individuals taking responsibility for their own health and well-being. This includes: staying fit and healthy, both physically and mentally; taking action to prevent illness and accidents; and the better use of medicines and treatment of minor ailments.”

The term self management is related specifically to living with a long term condition and has been defined as:

“The individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a long term disorder.”

Self management is a sub-set of self care. Throughout this document we are concerned with self care, but the principles invoked by the above definition of self management will be explored because they are conceptually very useful.





Quality of life for people with long term conditions

The relationship between health related quality of life and the severity of any underlying disorder is complex. We are learning more about the factors that determine health related quality of life and ways in which they can be managed to help people to improve their own quality of life. Some of these factors are presented in Table 1.

Table 1: Factors which determine health related quality of life

Tasks that someone with a long term condition is likely to have to manage for themselves:

- Complying with medication usage, ordering, and monitoring for side effects
- Exercise/activity planning, initiating, maintaining, and coping with setbacks
- Weight optimisation
- Adapting personal care, household and community activities
- Instigating behaviours that control symptoms or slow disease progression
- Adjusting to new social and economic circumstances and help family and friends make adjustments imposed on them by their condition
- Ensuring good food selection
- Adapting living and work environments, as well as possible social activities
- Stress management strategies
- Learning and adopting self diagnosis and disease monitoring activities
- Initiating communications with physicians, family, carers and acquiring the ability to access information and additional resources when required

Importantly, people's beliefs and expectations about their disorder and the role of healthcare in providing cure, care or support are major determinants of health related quality of life. Section 3 explores these concepts in detail.

Many healthcare professionals already attend to a number of these issues in their consultations. However, some might consider using a systematic interviewing style or more specific skills that can help facilitate meaningful lifestyle change for people they see who suffer from long term conditions. This book is designed to explore these issues in detail.



General principles of self care (see also 1.3)

Although the list in Table 1 might look daunting, the principles of self care belong to three domains:

1. **The biological domain** - understanding the medical condition(s): appropriate use of medication or other therapies, coping with set-backs, accessing appropriate levels of medical support.
2. **The psychological/cognitive domain** - understanding the role of unhelpful beliefs, thoughts or feelings
3. **The social/behavioural domain** - adapting to and defining new roles, responsibilities and activities

The Expert Patient Programme was devised by using the above principles. The philosophy that informs the programme is the so-called biopsychosocial framework (see section 1.3.2).

Everyone with a long term condition is already self managing to some degree; whether they want to or not. But not all are managing to their full potential. They may have good knowledge of a number of factors in Table 1, but may have misunderstandings or poor knowledge of others.

True collaboration between patients and professionals can compliment the traditional medical model of care. Using the biopsychosocial framework as a basis for the consultation can help people to explore, understand and manage not just their condition, but the way they live their lives.

This book will explore ways in which all healthcare professionals can incorporate elements of this framework into their everyday practice.



1.2 Why should we optimise people's capacity to self care?

KEY POINTS

- People with long term conditions want to self care
- People with long term conditions want healthcare professionals to do more to help them to self care
- Optimising the capacity to self care reduces hospital admissions and repeat visits to primary care
- Optimising the capacity to self care is highly cost-effective

- **Self care improves quality of life for patients**
A general review of self management programmes reported reduced severity of symptoms and pain, and improved life control, activity, resourcefulness, and life satisfaction. {20}
- **Self care improves patient satisfaction with the quality of their medical care**
Self management can work for many different groups of people. A study from 2004 showed self management improved satisfaction with care in a cognitively impaired group. {22}
- **Self care reduces the need for hospital admission**
After one year, participants in a generic skills programme had improved health status and had fewer visits to accident and emergency departments with fewer subsequent unscheduled admissions. {8}
- **Self care reduces repeat visits to primary care**
Follow-up visits to general practitioners reduced by up to two fifths {2, 3, 4, and 5}.
- **Self care delivers increased enjoyment and job satisfaction for the clinician**

Note: See Appendix 4 for in-depth evidence review



1.2.1 The magnitude of the problem

One in four people in the UK has a long term condition.

Table 2.- Disease prevalence in UK {68}

CONDITION	POPULATION AFFECTED
Diabetes Mellitus	1.3 million people with perhaps another million undiagnosed
COPD	600,000 people
Asthma	3.7 million adults and 1.5 million children
Arthritis	8.5 million in the UK
Epilepsy	400,000 in England and Wales (1998)
Mental ill health	One in six of the population, including one in ten children

The primary cause of death and disability in the world by 2020 will be chronic disease {69} and chronic disease management already accounts for 70% of US healthcare spending. {70}

In Dorset and Somerset (population 1.2 million), it would take three full-time GPs 23 years to see each patient with a long term condition just once.

We need to fundamentally change the way we manage and support people with long term conditions; we need to find another way to manage the demand.

Optimising the capacity of our population to self manage their conditions and their lives should be a core skill for all healthcare professionals. Research shows that supported self care reduces demand on services and allows clinicians to work in a more rewarding environment.



1.3 General principles that promote optimal self care

KEY POINTS

- Perceived health-related quality of life has a complex relationship with the severity of the underlying disorder
- Patients' beliefs about their condition and the perceived role of healthcare strongly predict healthcare seeking behaviour.
- Self care can only be optimised once beliefs and expectations have been assessed and addressed

1.3.1 Limitations with the biological model

The biological model promotes the ideal that every symptom has a physical cause, and every physical cause has a treatment. Further, the biological model states that reduced quality of life and level of disability are closely related to disease severity. Biological explanations of pathology tend to follow the same pathway; cellular pathology leads to organ pathology (impairment) which in turn leads to symptoms and then finally to disability and suffering.

The biological model is the foundation of modern medicine but has clear limitations, especially for people suffering from incurable conditions.

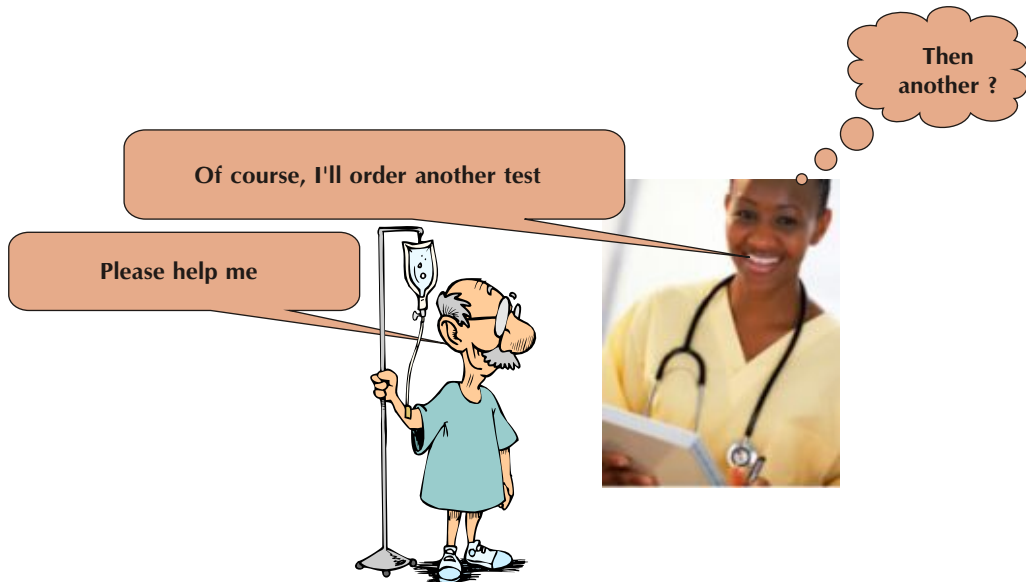
Once medical therapy is optimised, and should the patient still have intrusive symptoms, the clinician who practices solely in the biological domain can often feel frustrated and helpless - and so can the patient.

Biological Model



The biopsychosocial framework is a much more conceptually useful model for people with long term conditions. The clinician who works in biological, psychological and social domains can work with patients to address thoughts and beliefs about an illness and teach lifestyle adjustment and acceptance, rather than continuing to promise cures and never ending investigations.

Biological Model





1.3.2 The biopsychosocial model

KEY POINTS

The biopsychosocial model states that health-related quality of life is predicted by the interactions between the following factors:

- The severity of the underlying disease or disorder
- Associated symptoms
- Associated beliefs, expectations and anxieties
- Ensuing activity avoidance; changes in roles and responsibilities
- Associated changes in mental health

Each of the above factors needs to be addressed so that people with long term conditions optimally manage not just their condition, but also their lives.

Even the simplest medical problem encompasses all three elements of the biopsychosocial philosophy.

In clinical settings, most patients reduce their complex problems into a mere biological problem; the model that medicine and society have perhaps encouraged. But isn't sitting down and saying: *"I'm having difficulty going swimming with the children due to my skin condition - I feel itchy, anxious and self-conscious"* just as valid as: *"My eczema is playing up?"*

The ways in which the initial presenting complaint is elicited can make the consultation move in completely different directions. This simple scenario could be managed by a prescription for steroid cream or a discussion about anxiety or self-image.

This is the essence of helping people to self care. It's finding out what the problem really is.



1.3.3 Putting the biopsychosocial framework into practice. Cognitive-behavioral principles for non-psychologists

We are going to be talking about simple cognitive-behavioural principles that can be used by healthcare workers to help people gain control over their lives. The founding principles of cognitive-behavioural interventions are informed by the biopsychosocial philosophy.

All healthcare workers can use simple, cognitive-behavioural principles to help people with long term conditions to lead more fruitful lives.

KEY POINTS

The key principles of a cognitive-behavioural approach are:

1. **Appropriate consultation style**

A style that is supportive, non-confrontational and non-judgmental

2. **Assessing and addressing health beliefs**

People with long term conditions can become anxious and change the way they live their lives because of misunderstandings about their condition or the role of healthcare in providing support, care or cure.

It is vitally important that explanations for symptoms are not open to misinterpretation. The word 'arthritis', for instance, is vague and could be interpreted to mean anything from 'simple ageing' to 'disintegrating joint'.

Pathological explanations for a condition (often given by doctors) may not help people self-manage. The use of models can help people look at their condition in more helpful ways. An example is the person with back pain who has been told that they have arthritis; a pathological explanation that encourages passivity (pain = damage). A more helpful (and evidence based) model would present back pain as being related to changes in muscle fitness; an explanation that the patient can do something about

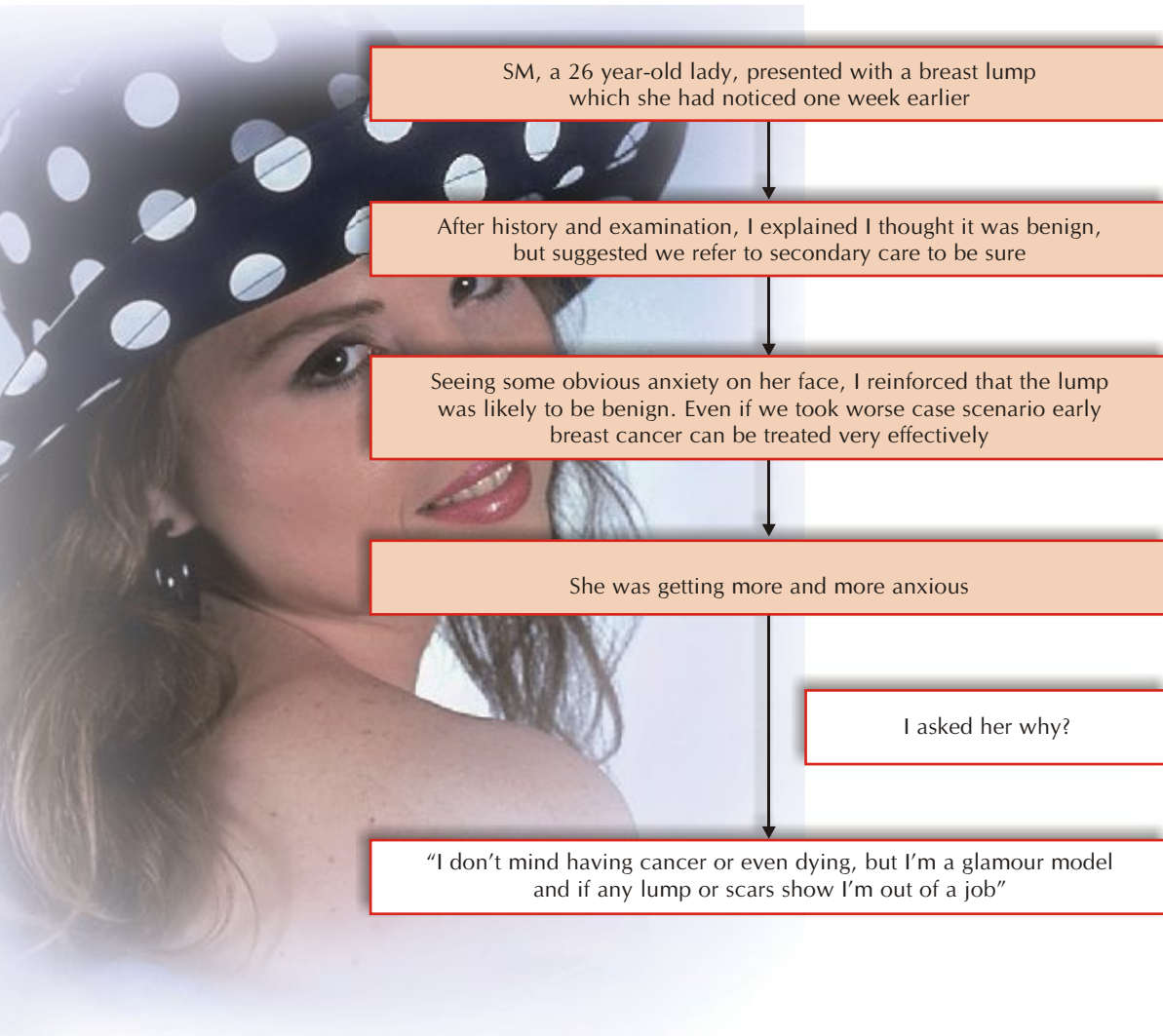
3. **Helping people to manage change**

People with long term conditions undergo lifestyle change as a result of their condition or treatment. Many people do not want to change but in many cases, change is inevitable. Being in a degree of control of the process of change is fundamental to reducing levels of distress and disability, thereby improving quality of life

Helping people manage and accept change in their lives is a core skill for all healthcare workers. An interviewing format that discusses change is important, as is an interviewing style that helps people plan for change

We are going to be exploring each of these principles in more depth in the coming chapters, but first, let's look at a couple of cases that illustrate the importance of these principles.

Case One



The doctor had assumed that he understood the patient's psychosocial framework without asking her - he had assumed it would have been the same as his own.

JH, 68 year-old gentleman, presented with chronic back pain. He had failed to respond to analgesia, physiotherapy, epidurals. He had seen the consultant rheumatologist who had suggested spinal surgery and was awaiting an outpatient appointment. He was depressed

"How are you managing your back problems?"

"I'm not, I'm on a waiting list, so I'm waiting"

"What is the back stopping you from doing?"

"Playing golf, it's too painful to swing a club"



lesson from a golf professional

- He was taught a new swing; although he lost 20 yards on his driving distance he was able to play golf twice weekly with his friends.
- Depression lifted.
- He cancelled the orthopaedic outpatients appointment.

Being on a waiting list can erode the capacity to self manage. Waiting implies inactivity and back problems, like most chronic conditions, tend to deteriorate with inactivity. Waiting lists are inevitable but perhaps we should refer to them differently and more actively manage the waiting period (see Angina study below).



1.4 First do no harm

KEY POINTS

- Explanations about diagnosis, prognosis or the role of healthcare can be misinterpreted by patients
- Mistaken beliefs and expectations can lead to profound changes in the way people think, feel and act
- Explanations should always be delivered using language that is not open to misinterpretation

It can take a lifetime to build up trust but only seconds to lose it. Years of work encouraging and supporting self care can be destroyed in a single consultation.

A patient who had been seeing a medical colleague was recently told by a hospital doctor:

“The tests showed you didn't have a heart attack this time, but heart attacks can present with quite trivial pains (on some occasions no pain at all) leading to a big problem if not caught in time. If you have any symptoms you think might be linked to your heart, call an ambulance and we'll see you again.”

The hospital doctor tried to be supportive and constructive, but the result was that the patient developed the following beliefs:

- he hadn't had a heart attack this time but one was imminent;
- he might be quite unaware of any early symptoms, so he could drop dead at any moment;
- his GP was unable to help.

Before his health beliefs were sensitively challenged, he was facing a life of anxiety and reluctance to engage in any stressful or stimulating activity and he was very likely to be a high-cost user of local healthcare facilities.

Perhaps after reviewing the patient's beliefs and worries about the nature of the pains, the hospital doctor might have said something like:

“Our tests show that your heart is very fit. There can be a number of reasons for chest pain. Some people get tight feelings in the muscles of their chest when they get tense or take unaccustomed exercise. You might want to think about gentle, routine exercise to get those muscles working a little better. If you have been feeling worried about your heart, I can reassure you again that there is no problem there.”

If a pathological explanation for a disease process is given (this might be inevitable), it is important to balance that explanation with other, more helpful information.



SECTION 2

**PRACTICAL METHODS TO SUPPORT
SELF CARE**



2.1 Introduction

KEY POINTS

Optimising the capacity to self care means helping people to manage change by:

- using an appropriate consultation style that:
 - addresses health-related beliefs and expectations and
 - promotes activity

Many of the skills are adapted from the psychology literature and can be used by healthcare professionals in their everyday practice. You are almost certainly using many of the skills already but we hope that this book contains something for everyone from the most inexperienced clinician to the most seasoned practitioner

2.2 The importance of change

Promoting optimal self care for people with long term conditions often means promoting sustainable, planned, lifestyle change. In order for change to be attempted, people should be ready, willing and able to change and this can be facilitated by using an appropriate consultation style.

None of us wants to be unwell, nor do we want our lives to change as a result of living with a long term condition. Most people want to incorporate the condition into their life and 'carry on as normal'. Importantly, many people expect the healthcare system to cure or adequately palliate their condition in order for life to continue unchanged.

Yet some sort of lifestyle change is inevitable after being diagnosed with a long term condition.

It might be necessary to consider lifestyle change in order to prevent deterioration in the medical condition. Examples include:

- concordance with medication;
- consideration of change in diet;
- planning to lose weight;
- maintaining and increasing activity.

Lifestyle change might also be imposed as a result of the symptoms associated with the condition. Many people alter their lifestyles because of:

- the direct effect of the symptoms;
- fear of symptoms;
- fear of doing themselves more harm. (See fear avoidance behaviour)

It is important to ascertain to what extent each of the above factors is in operation and to what extent the fear is being driven by misconceptions about the condition or by unhelpful or intrusive thoughts regarding the condition or the prognosis (see below).

Planning for the process of lifestyle change, and being in a degree of control of it, is an essential aspect of living with a long term condition.

Helping people to consider change is fundamentally important. We do this already in our everyday practice. Importantly, we should be working with patients to make planned change a priority.

Patient: *“It’s too late; the cigarettes have already done the damage.”*

(The patient is not willing to change.)

Doctor: *“They have already done some damage. They continue to do more damage the more people continue to smoke. Stopping now will prevent the damage from getting worse.”*

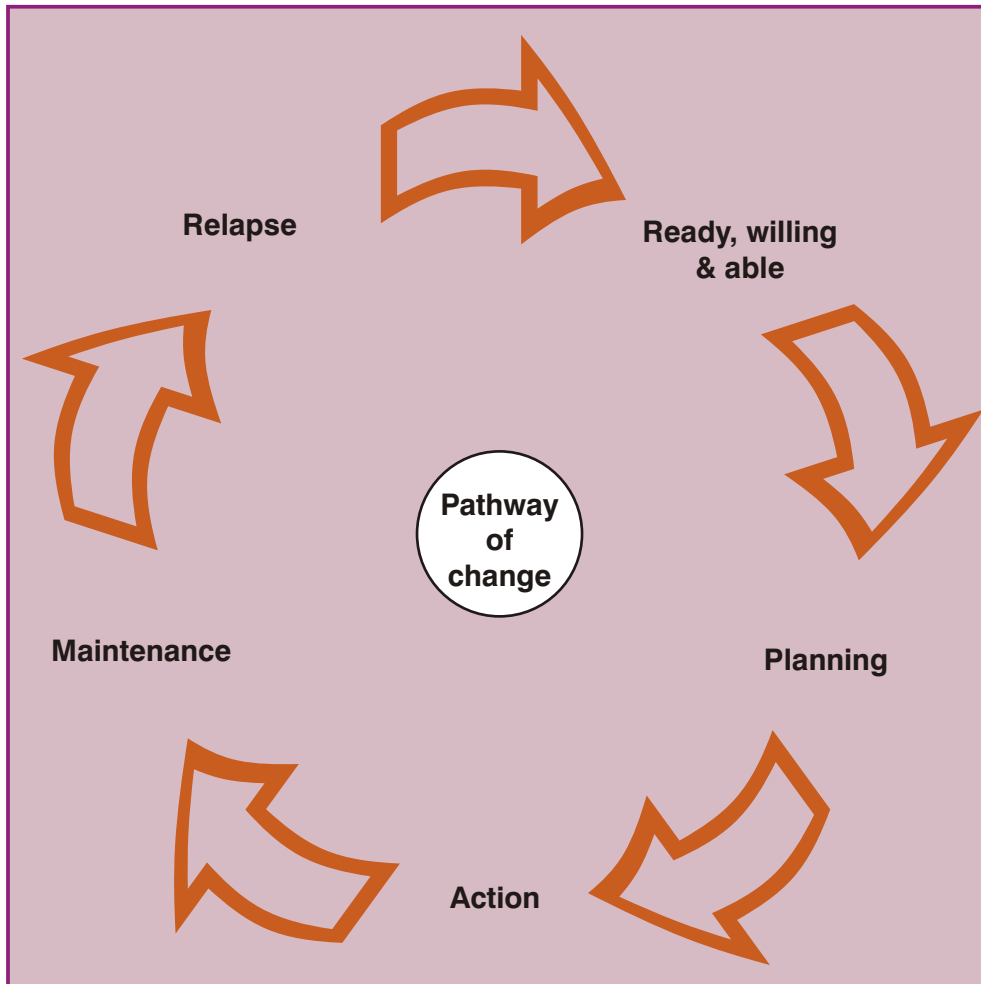
If this fails a cost-benefit analysis of stopping smoking might promote willingness (see section 5.7).

In order to help people to plan for change, there are a number of key concepts that we are going to discuss, in particular:

1. The pathway of change
2. Interview styles that promote change
3. Interview content that promotes change



2.2.1 The pathway of change



Modification of Prochaska, JO Diclemente, C.C. 'Stages of Change' model

Assessing motivation to change is a key aspect of promoting self management. Readiness to change is a dynamic process; we all have numerous change agendas in our lives at any one time.



2.2.2 Ready, willing and able

People change when they are ready, willing and able to do so. This section reviews this concept, using examples of interview formats that can help to promote lifestyle change. These extracts interviews use a motivational style that is explored further in section 2.3

Ready

Is change something that is top of the agenda now or is change planned for the future? If the future date is very vague (eg “*next year*”) this can be a form of denial - it often implies readiness is lacking:

“Stopping smoking is important to me, but it's not the most important thing right now . . .” “... I want to, but not now.”

Change needs to be prioritized. Helping people to see change as a high priority can promote motivation to consider change.

Barriers to readiness to change

1. The most important barrier is the belief that medicine has something to offer in terms of investigations or interventions:

“I know this chronic fatigue is caused by a virus. Please can I see a virologist?”

“Can't you give me that tablet I've heard about to make me lose weight?”

“Can you send me to another consultant for an opinion - there must be something that can be done for the pain?”

Helping people become ready to plan for change means sensitively exploring and perhaps challenging their beliefs and expectations about the role of healthcare. Discussing goal-directed change is a fruitless and frustrating task for all parties if people are not ready to change because they have an expectation that medicine has more to offer.

2. A further important barrier to readiness to change is the belief that activity-related symptoms are the body's way of telling us to avoid activity.

This fear avoidance behaviour is innate, but can be accentuated by misinterpretation of data provided by healthcare professionals.

Willing

Is change fundamentally important according to the person's value system?

The importance of change depends upon the degree of discrepancy between what is happening at present and what one values for the future. As long as present reality is found to be within desired limits, no change is indicated. It is when things are sufficiently different or far removed from the desired or expected ideal that motivation for change begins. In order to instigate change, develop discrepancy in order to enhance the perceived importance of change:

Doctor: *“Is life just as you'd like it right now; are there things that you feel you would like to change?”*

Many people define themselves according to their actions- their social roles and responsibilities: “*I am a caring father, a good husband*” etc. If intrusive symptoms prevent the caring father from carrying his children to bed (for instance), his social role is threatened and this can lead to profound feelings of loss, guilt or frustration. A need to regain that self defining activity is a profound motivation to change. In this instance, one important goal of self management would be to work specifically on this task using a graded exercise programme (see below)

Cost-benefit analysis can be very useful to identify why willingness might be lacking (see section 6.8)

Able

Sometimes a person feels willing but not able to change: “*I wish I could.*”

To be able to change requires the patient to believe that change is possible (general efficacy) and to believe that they can achieve the change (self efficacy). Both elements need to be present in order for change to occur.

General efficacy

A good example to demonstrate general efficacy is the issue of recycling. Many people are ready, willing and have the self efficacy to recycle, but if they do not believe that their efforts can actually make a change (nationally) they do not recycle.

Self efficacy (self belief/self confidence)

Rollnick [12] demonstrates that if people are asked how likely they are to succeed in a particular action, the answer is a reasonably good predictor of the actual chance of success. This is the concept behind self efficacy, which in turn is key to optimal self management. Section 2.3.1 explores self efficacy in more detail.

Many people want to make the change, believe it will make their life better but don't think they can manage the task and have fear of failure.

If self efficacy is low:

- reinforce self efficacy by considering other times when the patient has been able to succeed in attaining goals;
- reset the change/goal, or talk about a change menu. (This is explored in greater detail below in section 2.3.1).

Many people try hard to be the person they think they ought to be (see acceptance). This can lead to a series of unrealistic goals and either failure to reach the goals or attainment of the goals becomes a grueling process (see also below).

All three elements (ready, willing and able) should be present before change can be planned and the plans acted upon.

After assessing the patient's own ready, willing and able status it is important to focus on the tasks or activities that the patient would like to change.

Example: *A smoker presents to a clinic, keen to stop smoking. After assessment he or she is ready and willing to stop but does not feel able. If the clinician spends time talking about lung cancer or chronic lung disease, this will just reinforce willingness (something the patient has already achieved). Time spent reinforcing self efficacy might well be more fruitful.*

Over-supporting willingness can be counter productive as this may imply that you don't understand the patient's beliefs and problems. It also may be perceived as nagging which is likely to erode willingness. No-one likes being told what to do.

2.2.3 Planning

People begin thinking about how they can make the change they desire, make plans, gather additional information and then take some steps towards stopping old behaviours and /or starting new, more productive behaviours. During this phase patients often become more and more committed to making changes. Help with skill acquisition at this stage is important.

2.2.4 Action

People start to implement changes. During this stage they may tell other people that they are making the change and might well need support and encouragement to help them continue the action. During this stage, concentrate on congratulating them for making a start and highlight any success however small it might be.

2.2.5 Maintenance

After people have achieved the change, it is then important to avoid slipping back into bad habits. This can be a very difficult stage as all the euphoria of making the change disappears. The temptation is to start thinking fondly about the pre-change state. Reminding them of the reality of the pre-change state can be of great help.

If change has not yielded the expected results, maintenance is challenged:

“If I lose half a stone, I'm bound to find a new girlfriend.”

The clinician should help the patient reinforce all the benefits that the change has actually promoted (health benefits of weight loss), before reviewing the new goal (finding a new girlfriend).

It is often that case that another plan will be required, due to the goal not being fully achieved, or a new goal being desired, but ensure that self efficacy is enhanced by demonstrating how they managed to achieve change.



2.2.6 Relapse

Relapse is normal and should be expected. The cycle is restarted. The cycle can be re-entered at any stage. It is important to develop an action plan for relapse at the planning stage. When relapse occurs, it is important to identify and selectively reinforce previous achievements.

2.3 Consultation styles that promote self management

2.3.1 Motivational interviewing

Motivation to change should be elicited and not imposed by the clinician. Confrontation or coercion can lead to change but more likely will lead to alienation.

Doctor: *“If you don't lose weight you are going to die very soon.”*

Patient: *“I've been fat since I was five. I cannot lose weight, so if I'm going to die soon I'm not going to spend what short time I have left on a diet.”*

It is far more effective and powerful to use the patient's own values and goals to stimulate behaviour change.

“Motivational interviewing is a directive, client-centred counselling style that elicits behavioural change by helping clients to explore and resolve ambivalence.”

Rollnick S., & Miller, W.R. (1995). What is motivational interviewing? *Behavioural and Cognitive Psychotherapy*, 23, 325-334

Motivational interviewing (MI) is a style of interviewing that is supportive, affirmative and non-judgmental and that helps people to consider and plan for change. The style is entirely patient-centred, but aims to support lifestyle change by developing discrepancy and selectively supporting desire for planned change.

There are four general principles behind motivational interviewing:

1. Express empathy
2. Support self efficacy
3. Accept what you are told
4. Develop discrepancy

1. Express empathy

Empathy involves trying to share in and understand the patient's experiences. Evidence has shown that when patients perceive empathy on the part of the doctor they become more open to gentle challenges about lifestyle and beliefs.

Being overly empathetic can be interpreted as being insincere.

Doctor: *"I know how you feel"*.

Patient: *"No you don't; how can you possibly know how I feel?"*.

Finding the right level is a skill that most primary care clinicians are particularly good at, having already established a relationship with the patient, but, if unsure, you can phrase your empathy as a question: *"Was that as nasty as it sounds?"*, or *"I've been told that type of pain can be severe, how was it in your case?"*, or *"Many people find that incredibly annoying, how did you find it?"*. The answer to the question will often establish whether you have established the correct empathy level or not!

2. Support self efficacy (self belief)

A belief that change is possible. As it is the patient that needs to instigate and maintain change, it is important for the clinician to be supportive rather than directive.

In order to feel able to change, people need to believe that change is possible and that they can achieve the change for themselves.

Ways of supporting self efficacy

- Produce a menu of change for the patient to choose from. Presented as changes that have already been made by people in a similar situation that have been successful i.e. *"So it looks as if we agree that it would be good if you could lower your alcohol intake, there are lots of different ways of doing this. Some people find particular success with..."*. This demonstrates that change is possible.
- Use positive examples from the patient's previous experiences when they did manage to instigate change. This could be giving up smoking, losing weight, changing job, putting time aside to study for an exam, starting a family etc. This demonstrates that they may be able to change as they have done so in the past.

3. **Accept what you are told**

Often we are told a sequence of events that we find very difficult to believe, or about a symptom that sound exaggerated, such as: *“I have pains from my toes through my whole body into my head.”* If this happens accept the description of events - acceptance builds empathy.

4. **Develop discrepancy**

“Motivation for change occurs when people perceive a discrepancy between where they are and where they want to be.” (Miller, Zweben, DiClemente, & Rychtarik, 1992).

Doctor: *“Is life just as you'd like it right now; are there things that you feel you would like to change?”*

2.3.2 Other counselling skills

Like most good consultation styles, motivational interviewing also embraces the concepts OARS and FRAMES:

OARS

- **O**pen-ended questions
- **A**ffirmations
- **R**eflective listening
- **S**ummaries

Open-ended questions

Questions that invite reflection and consideration and which cannot be answered with a “yes/no/twice/never” style answer. (Closed questions can be used to move the consultation forwards).

Affirmations

Statements that recognise the patient's strengths - affirmations should be congruent and genuine. Affirmations can be significantly helpful for people who are not used to compliments:

“Despite being addicted to drugs you have managed to hold down a job - that takes great strength.”

“You didn't want to come today, but you still managed to turn up.”

“Well done for coming to the consultation on time, a lot of people this morning have not managed it.”

Reflective listening

Statements that highlight and summarise the clinician's understanding of the patient's point of view and that are offered as debating points, rather than points of fact. Reflective listening helps the clinician to understand the patient's perspectives:

“It seems that you are really committed to exercising more often, but are not sure what exercises to try..is that the case?”

Summaries

Build rapport, call attention to salient elements of the discussion and also give an opportunity to shift direction or attention:

“Let me stop you for a second and summarise what we have been talking about. Correct me if I get anything wrong. It sounds as if the exercise you have started is helping, but you are finding the process very slow and frustrating. It also sounds as though you are wondering how much better your back will ever get, and if this means you may have to change jobs. How much better do you think your back will have to get for your current job to be sustainable?”

FRAMES

- **F**eedback
- **R**esponsibility for change lies with the patient
- **A**dvice
- **M**enu of change options
- **E**mpathic counselling
- **S**elf efficacy enhancement

Originally devised by Miller and Sanchez (1994).

*“Well Mark, over the last few weeks you seems to have understood everything we've discussed about managing diabetes (**F**), and I think you've made an excellent start to changing the way you eat (**F,S**). I suggest you now think a little more about increasing your exercise (**A**). But what exercise, and how often? Perhaps cycling, swimming, golf (**M**) it's up to you (**R**). You've told me how difficult it is for you to think about exercise, (**E**) but it is important (**F**). You've achieved so many good things in your life; I have faith that you can make a good decision (**S**).”*



2.4 Consultation content that promotes self care

“We would all self manage, all the time, if there was no such thing as a modern health service”

- all medical interventions should support self care;
- people only optimally self care once they know that their medical condition is optimally managed.

Optimising the capacity to self care for people with long term conditions means:

KEY POINTS

- Ensuring evidence based medical interventions have been discussed and offered
- Ensuring the patient is aware of the probable outcomes and limitations of the medical intervention and knows that for an optimal outcome, they must take some responsibility for managing their condition and their life
- Stopping offering medical interventions once the medical condition is optimised

The latter offers the greatest chance of optimising self care, but will only truly be embraced by healthcare workers who have knowledge and skills that support self care.

We suggest that interviews specifically address the three biopsychosocial domains. We suggest that the interview style is one that facilitates change (see above), whilst the content should include the following:

Biological assessment

- Is the diagnosis certain and is evidence-based treatment optimized?
- If not; discuss options
- If treatment is optimised; does the patient know that this is the case and have they accepted this? (see acceptance, below)
- Do they understand the need for their current treatments? (efficacy, side-effects, when/if to take more or seek further help)

Psychological assessment

- What are the patient's beliefs about the nature and cause of their condition?
- What are their beliefs about their prognosis and the role that they can take in improving their own quality of life?
- What are their beliefs about the role of healthcare in providing care, cure or support?
- Do they have evidence of intrusive, unhelpful thoughts?

Quality of life for people with long term conditions is closely related to the perceived severity of the condition and also to their thoughts and feelings about the condition and the impact that it is having on their lives. We know that many people with long term conditions have intrusive, unhelpful thoughts about their condition and many of these thoughts are triggered by misconceptions about their condition (see beliefs, below)

The following simple exercise demonstrates the pivotal role of reviewing thoughts and feelings.

Past Medical Problem	Feelings	Thoughts
Wisdom teeth removal 1974	Confusion Surprise Loneliness	<i>“Hospital food was horrible. . . ”</i> <i>“I never slept a wink- wards were so chaotic. . . ”</i> <i>“I hope my children never have to go to hospital.”</i> <i>“Happened during exams. I always seems to get problems at the most inconvenient times . . . ”</i>

Understanding these thoughts might help communication with a parent presenting with a child who has toothache.

Social assessment

- Are they able to self care in terms of activities of daily living?
- What aids might be appropriate?
- What are their goals, with regard to their levels of activity and social roles and responsibilities?
- Do they think that these goals are reasonable?

People change the way they live their lives as a result of having a long term condition and can often undergo enormous changes in their roles and responsibilities.

Some of these changes are inevitable - a 65 year-old with multiple pathologies is perhaps not going to run a marathon again (see acceptance). However, some changes can be brought under a degree of control. The next sections will explore consultation content in more detail. Specifically, we are going to be looking at beliefs, thoughts and feelings (section 3), then behaviours (section 4).



SECTION 3

BELIEFS, THOUGHTS AND FEELINGS



3.1 Introduction

KEY POINTS

- Health-related beliefs and expectations are strong predictors of quality of life
- Many people develop health-related anxiety as a result of misconceived beliefs and expectations
- Health-related anxiety can lead to healthcare-seeking behaviour, avoidance of activity and profound changes in social roles and responsibilities

Many people change the way they live their lives because of fundamental misconceptions about their condition. Many of these misconceptions are unhelpful, can trigger health-related anxiety and can lead to profound changes in quality of life. Cognitive behavioural therapy (CBT) is a specialised technique that addresses misconceptions and unhelpful thoughts and can help people to gain control over the way they live their lives. All healthcare professionals can use elements of cognitive behavioural principles in their everyday practice, even if it is only used for assessment of a patient's problem to allow referral on for further help.

The importance of beliefs has already been widely accepted in all areas of medicine. The effect of believing that one is receiving an effective treatment is so strong that placebo is the standard against which new medication must be tested.

3.2 Beliefs

Optimal self care is compromised if:

- patients believe (expect) that medicine has more to offer in terms of diagnosis or treatment;
- patients have fundamental misconceptions about their disorder.

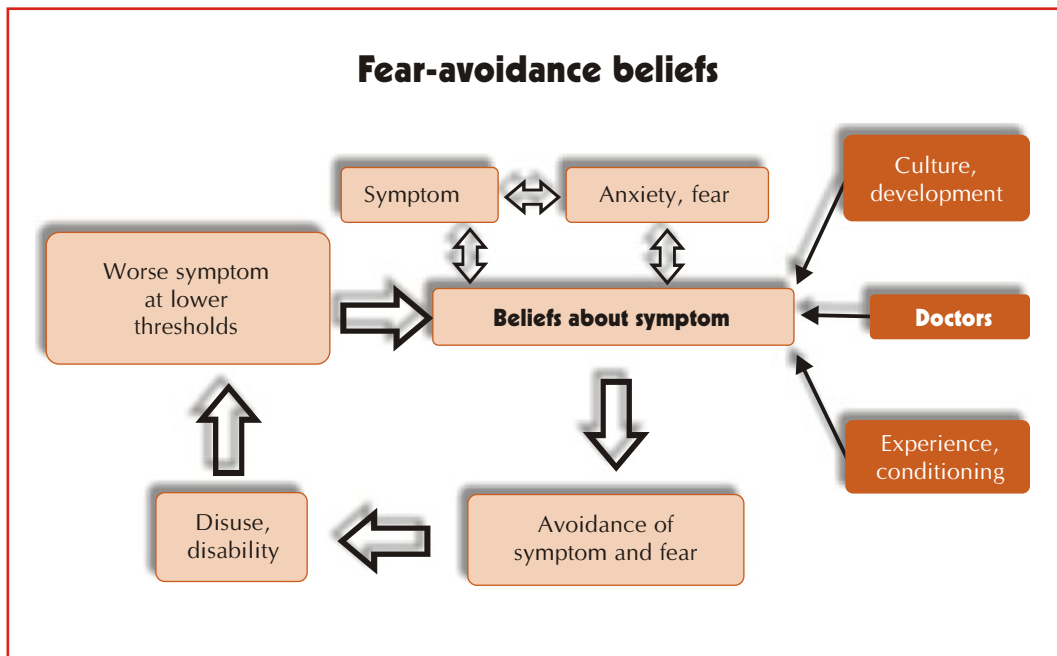
Each of these issues should be explored and (possibly) sensitively challenged in order to help people move towards contemplation of optimising self care



3.2.1 Fear and avoidance behaviour

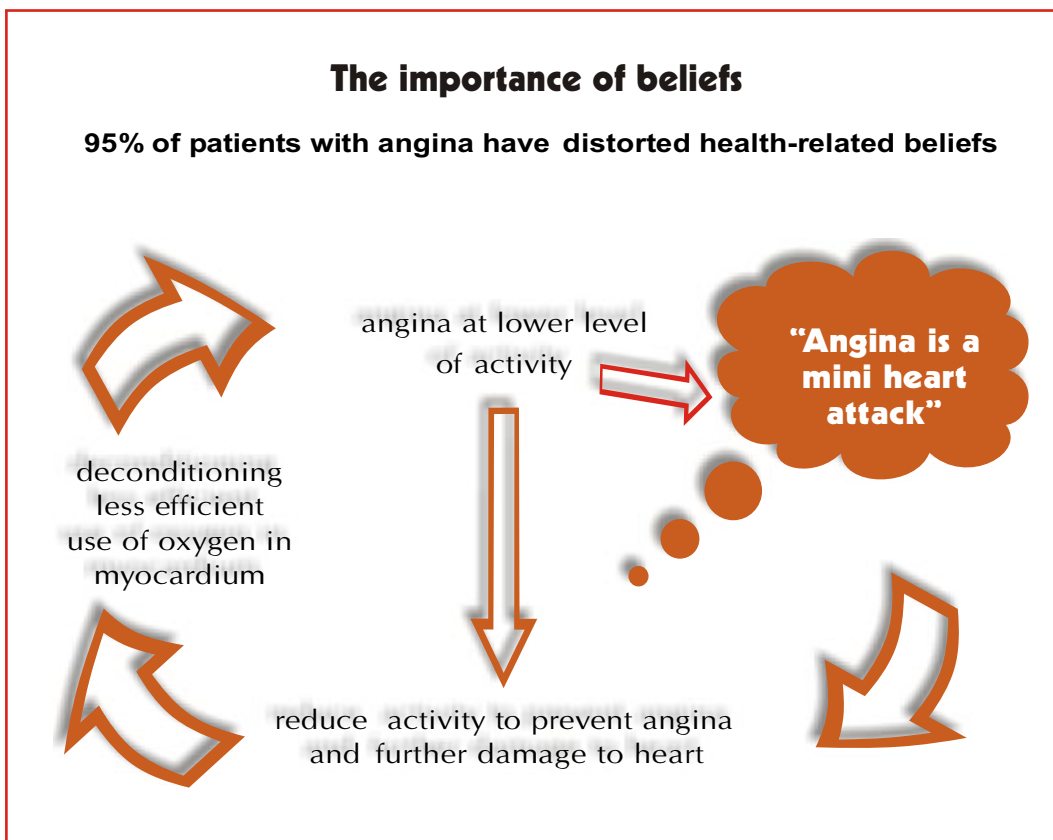
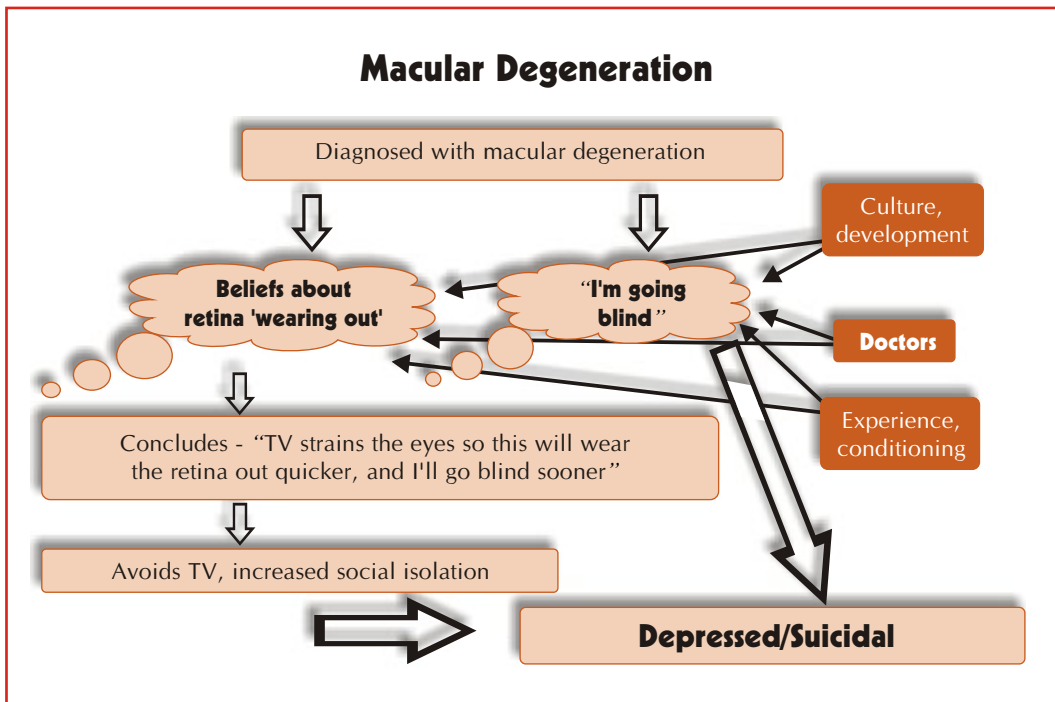
Many people fear their symptoms or what they believe their symptoms might mean. Many people also fear exposing themselves to situations that might bring about a worsening of symptoms.

Not unnaturally, this can lead to changes in lifestyle and avoidance of activity. Such fear-avoidance behaviour can lead to unhelpful lifestyle change, feelings of being out of control, inadequacy or depression.

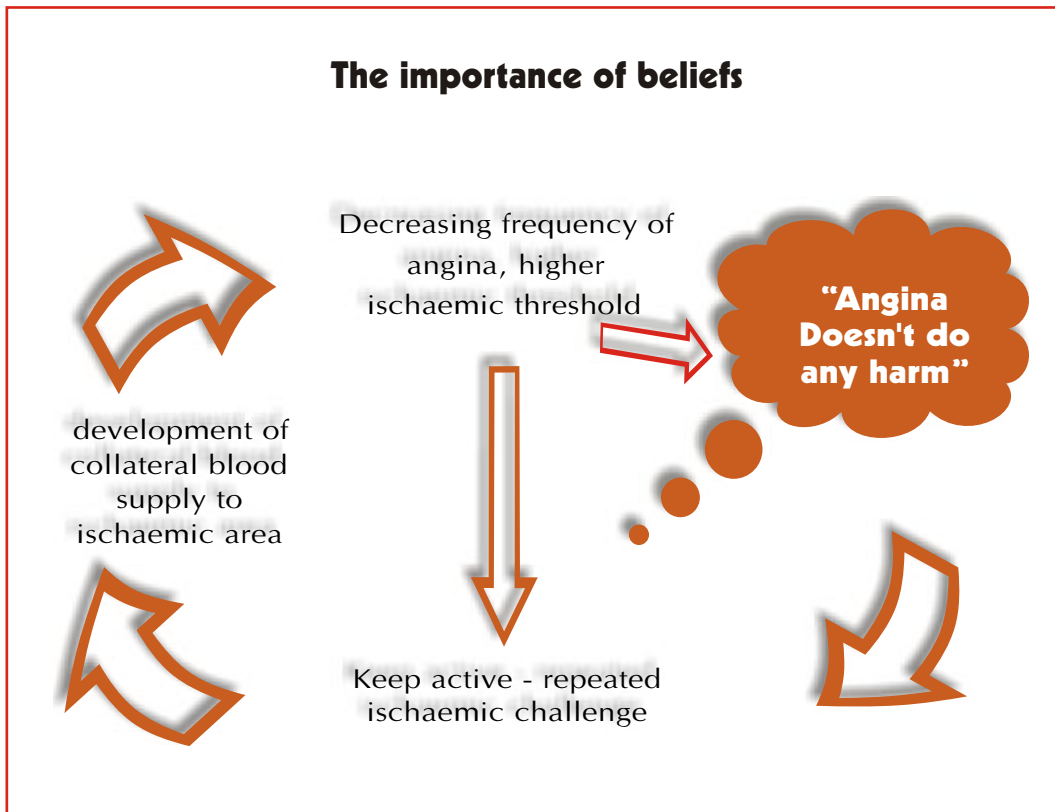


Vlaeyan et al 2004

Health-related misconceptions, leading to fear and avoidance behaviour have been shown to be important predictors of lifestyle change, and reduction in quality of life, for a range of long term conditions. We present two such conditions: macular degeneration and angina pectoris.



Lewin, B. 1997, *Journal of Psychosomatic Research* 43:453- 462



Lewin, B. 1997, *Journal of Psychosomatic Research* 43:453- 462

Challenging angina misconceptions can produce profound results.

Angina Management Programme, Lewin, B, 1995, *British Journal of Cardiology*, 2, 219-26.

This study was a cross-over trial of patients on the waiting list for coronary artery bypass grafts (CABG). It involved 82 patients, all of whom remained on the waiting list but used this time to enrol and follow an angina management programme addressing all three domains (bio, psycho, social)

At one year after starting the programme:

- 30% of patients had no angina
- 70% of patients had reduction in episodes of angina
- 57% of patients had improvement in exercise duration
- 72% of patients had reduction in self reported disability (SIP)
- 50% of patients of patients were removed from CABG list, as their operation was no longer necessary as judged by their clinician

Long term follow-up (Lewin RJP, *British Journal of General Practice*, 2002: 52:194-201) showed that approximately 50% of the improvement in disability was explained by changes in misconceptions about angina. Challenging these misconceptions (*"angina is a mini heart attack, every episode of angina damages my heart"* etc) led to improvements in quality of life.



3.2.2 Challenging misconceptions

Many of us define ourselves according to our beliefs. People die for their beliefs. Challenging beliefs can lead to alienation. We suggest that a motivational interviewing format is used as described above.

Alternative explanations might be brought up as debating points and patients supported in modelling possible outcomes:

Doctor: *“ I understand that you have been told that your fibromyalgia is caused by your muscles wasting away; is that what you have been told?”*

Patient: *“Yes. I have been told that the muscles are falling apart.”*

Doctor: *“How does that make you feel?”*

Patient: *“Terrible; I just don't know where it's all leading.”*

Doctor: *“You know, the medical view is that we don't fully understand fibromyalgia. What we do know is that the muscle pain seems to be caused by muscles going into cramp easily. In the medical literature at least, the evidence that the muscles are falling apart is very sparse indeed. In fact, not using the muscles can lead to wasting and cramp. People who remain active are those who suffer much less in the long term. What do you think?”*

3.3 Thoughts and feelings

Sally a 48 year-old primary school teacher with chronic back pain, develops a new pain in her lower back after carrying out exercises suggested by her doctor. She could have numerous thoughts but here are a few. See how they affect her feelings and behaviour:

	1	2	3	4
Thoughts	<i>“Oh no, what now? That's another disc gone.”</i>	<i>“Why was I told to do those exercises they have simply eased one problem but created another?”</i>	<i>“I can feel the muscles in my back becoming stronger.”</i>	<i>“I think I have overdone the exercises.”</i>
Feelings	Depression	Anger	Relief	Frustration
Behaviour	Social withdrawal, reduced physical activity	Stops doing the activities. Anger with doctor	Increases levels of exercise	Continues the exercises but at a lower intensity

In this example it does not actually matter what the real cause for the pain was. Sally will experience altered feelings and behaviour according to her thoughts.

Now let's suppose that Sally goes back and sees the doctor, who examines her back and tells her that she has strained a muscle in her back, but the actual bones and discs have not been damaged. She now needs to rest the muscle for a few days then slowly increase the exercise again.

	1	2	3	4
Thoughts	<i>“Well, that explains the pains.”</i>	<i>“Why didn't the doctor tell me this could happen?”</i>	<i>“Why did he tell me the bones and discs were normal? Does this mean that the exercises could actually damage them?”</i>	<i>“Why does this always happen to me? Every time I start to get somewhere, something new happens to knock me down again.”</i>
Feelings	Relief	Anger	Anxiety	Depression/frustration
Behaviour	Does as suggested with rest for three to four days, then gradually returns to activity	Sees the doctor as the cause for the pain, with blame and animosity	Stops all exercise and does not try again - takes lots of analgesia	Reinforces her belief that there is nothing that can be done for her back.

In order to promote optimal self care, it is important to identify health-related misconceptions (beliefs) that might be leading to unhelpful or intrusive thoughts that could, in turn, lead to activity avoidance or withdrawal from social roles or responsibilities.

3.3.1 Unhelpful thoughts

1. Overgeneralisation
2. Crystal ball
3. Dwelling on negatives
4. Dismissing positives
5. Labelling
6. Apportioning blame
7. Light switch thinking
8. Size alteration
9. World instructions

“Jane, a 56 year-old lady came to see me with a weight problem which she had been trying to control for years. She had been on every diet that she could find, but despite her best efforts she has constantly failed to maintain weight loss. She told me ‘I will never lose weight.’

“We worked on this thought and between us concluded that a more accurate representation was: ‘So far I have been unable to lose any weight in the long term despite my best efforts.’

“After some more thinking we moved to: ‘I have managed to lose some weight in the past but despite my best efforts the weight has all returned again.’

“This thought more accurately represented her point of view and led on to further, more useful discussion, reflecting on the positive steps that she had taken in the past when she had lost weight and discussion around reasons for ensuing weight gain.”

Helping people to identify that their thoughts might not be useful can support optimal self care.

1. **Overgeneralisation**

These thoughts contain 'always' and 'never' statements:

“I never get a moment to myself.”

This could be true but is very unlikely. Much more likely is:

“I don't get as much time to myself as I would like.”

The word 'always' can also be used as a display of emotion to qualify the thought:

“I am always the last to be asked.”

This can lead to an unhelpful thought which might become believed and in turn might make the feelings worse.

2. **Crystal ball**

The assumption that you are able to predict what other people have been thinking or will think, or the assumption that you have the ability to predict the future:

“I'm bound to get breathless if I go for a walk with friends and they are bound to think I'm a wimp.”

3. **Dwelling on negatives**

Concentration only on the negative. You might tell yourself that someone doesn't like you if they turn up late to a dinner party you were giving, despite them bringing you a present, apologizing, and seeming to have a great time. Concentrating on negative events brings a risk of becoming depressed.

4. **Dismissing positives**

Similar to dwelling on negatives but from the other end of the spectrum you dismiss your success in life as 'not counting' or that it is something that anyone could have done.

5. **Labelling**

Jumping to conclusions, about yourself or someone else: *"I'm a failure."*

6. **Apportioning blame**

These thoughts can be apportioned unrealistically to oneself: *"It's my fault that I have depression."* Alternatively they are apportioned to others unrealistically: *"I only have diabetes because the local shop has chocolate on sale right next to the checkout."*

7. **Light switch thinking**

Everything must be a full success or a complete failure. For example, you train for a race, your time is better than you have ever dreamed of obtaining but you still get beaten by someone you thought you were going to beat, so you consider yourself a failure, you give up training and never race again. Or a diabetic on a diet is so disillusioned with herself after having a bowl of ice cream that she considers that all her efforts to lose weight have been wasted and that she might as well eat whatever she wishes.

8. **Size alteration**

Exaggerations such as: *"The whole world is against me."*

9. **World instructions**

Thoughts that are directed at oneself in the future: *"I shouldn't eat that chocolate bar."* Unfortunately, these thoughts may make us feel rebellious and annoyed at being told what we should or shouldn't do, and the net result is we are actually urged to do the exact opposite.

In clinical practice, people can be asked to write down their thoughts then review the above list to try and identify any unhelpful thoughts present.

This process has greater impact if done by the patient themselves, rather than the clinician highlighting the unhelpful thoughts. This works very well as an exercise to do between clinic appointments.

All the above processes describe negative thoughts, which form the majority of unhelpful thoughts. However, positive thoughts can be just as unhelpful: *"I can eat whatever I like today as I'll start a diet tomorrow"; "I can stop smoking whenever I want"; "I know better than my specialist."* These thoughts can easily lead to as much trouble as negative thoughts, but they should be reviewed along the same lines as negative thoughts.

After the unhelpful thoughts have been identified, one might be able to gently challenge them in order to promote self efficacy and contemplation of change. The next section discusses ways of gently challenging unhelpful thoughts.



3.3.2 Managing unhelpful thoughts - cognitive restructuring

These are a number of simple techniques that can be used to challenge unhelpful thoughts that are holding people back from contemplating change

Cognitive restructuring techniques

1. Highlighting the unhelpful thought.
2. Reviewing true events
3. Using the best friend method
4. Putting your thoughts to the test
5. Making the thoughts more balanced
6. Changing the grammar

1. Highlight the unhelpful thought

Start by repeating the thought aloud or writing it down. Ask the patient how much they agree that it is true on a scale from 0-100. Write this score next to the thought.

Patient: *“Oh no! What now? Everything must be getting worse in my back.”* (Score 95)

This presenting thought is clearly unhelpful. Highlighting this over-generalisation might lead to the more accurate and helpful thought:

“I don't know what is causing the new pain in my back. I'm worried it might mean the back is getting worse.” (Score 100)

This already sounds a lot less threatening and gives an opportunity for further discussion.

Now go back and re-score the original thought score 95, changes to 40. This reinforces the defusing of the original thought and increases self efficacy by demonstrating some ability to move forward.

2. Review true events

After highlighting the unhelpful thought, it's useful to review events

Patient: *“Why was I told to do those exercises? They have eased one problem but created another.”*

Reviewing true events might highlight that the doctor has helped in the past and would not have suggested treatment that he or she did not think would help. It might be that the new pain has nothing to do with the exercise or perhaps the exercises are being performed incorrectly, but rather than guess, try to find out what the true course of events was.

3. Use the best friend method

Many people say that they are able to give advice to others but seem unable to help themselves. When such people are confronted with an unhelpful thought, it can be useful to ask them to imagine that they are listening to their best friend who has just told them the same thought. What advice would they give? Example :

Peter (a teacher), diets for four weeks but fails to lose any weight. He might think: *“I’ll never lose any weight.”* This is clearly not helpful. The clinician could challenge this thought, but a best friend might well not. Repeat the thought aloud to the patient and ask what they would reply to a very good friend who has just said this to them. They might reply: *“Don’t worry, I think it’s amazing how you manage to have so much energy at school and all the children seem to love you. You also have a lovely family and despite being in pain all the time with your back, you are always there for me when I need some help. The fact you have managed to stay on the diet for four weeks is an excellent achievement and I’m sure if you stick at the weight loss programme, you will get good results just like you have achieved in other aspects of your life.”*

4. Put your thoughts to the test

Arthur is a 64 year-old gentleman who suffers from panic attacks. During these attacks he thinks he is having a heart attack. Arthur can be taught to safely test this theory. If he is having a heart attack it means that the heart is being damaged and will not work to its normal level. Ask Arthur to stand up; if he can do this, suggest that he starts to slowly walk around the room. If he is able to do this, prompt him to plan to do some light exercise to prove that his heart is as strong as ever.

5. Make the thoughts more balanced

Some thoughts demonstrate light switch thinking as described above. These can be addressed effectively by placing the thought more in the reality, between the full-on and full-off limits.

Susan has recently been diagnosed with epilepsy. She has had to stop driving, but she is a housewife who needs to take her two children to school and pick them up daily. Susan’s thoughts are: *“I will never be able to get the children to school if I cannot drive. Social services will then come and take my children away.”*

These thoughts are extreme and could lead to high levels of distress and unhelpful behaviours. Start by helping Susan to identify that the thought is not helpful and then help Susan to look at her situation in more useful ways: *“I will find it a lot harder to get the children to school and pick them up on school days. I can inform the school about the problem and they might be able to help or at least keep on record that it is difficult to get the children to school and understand if they are occasionally late.”*

Balancing the thought may not produce an extensive list of all possible solutions. Susan will most likely find these herself once the initial thought has been balanced making change possible. Solving the problem herself will add to her self efficacy.

6. Change the grammar and put to test

Harold, a 78 year-old gentleman with COPD is asked to go for a walk with friends. He might have a thought: *“I will only be able to walk 100 yards before I get tired and have to stop, this will be embarrassing and will annoy my friends.”*

This is not helpful. Note how much more benign it becomes if *“might”* is used instead of *“will”*: *“I might only be able to walk 100 yards before I get tired and have to stop, this might be embarrassing and might annoy my friends.”* This thought can then be put to the test i.e. Harold could ring his friends, and if they are close friends they might already know what his exercise limits are and be more than happy to proceed at a rate that he can manage.

(A much better outcome than medicalising the problem, perhaps leading to a request for oral steroids)

(See also Appendix 2: 'Drop the why' and 'Drop the but')



SECTION 4

PROMOTING BEHAVIOURAL CHANGE



4.1 Introduction

Often, a desired outcome from any self care intervention is a change in behaviour. This might comprise:

- a reduction or control over unhelpful behaviours, such as drinking excess alcohol;
- an increase in activity, with more sense of control over activities of daily living;
- a redefinition of social roles and responsibilities (work, friends, family);
- more appropriate use of healthcare resources.

People engage in optimal self care behaviours once the following have been addressed by using an appropriate consultation style:

- beliefs and misconceptions about diagnosis;
- beliefs and misconceptions about prognosis;
- beliefs and expectations about the role of healthcare;
- unhelpful thoughts.

Once the above have been addressed (see above), patients can be helped to set themselves social and activity goals for the future.

4.2 Functional assessment

Many people define themselves by their ability to carry out key activities. Symptoms that interfere with these key activities threaten the ability to self care and also uniquely threaten the sense of self. These key activities may be:

- activities of daily living (ADLs) such as washing, cooking, shopping;
- hobbies, sports;
- family and other social activities;
- work.

Any assessment of current function must attend to the above. In order to plan a programme that is designed to optimise self care, it is important that self defining activities are discussed in detail, as the self care programme should attend to these specifically.

“A psychologist friend gave a talk to people with osteoporosis in a church hall. She had prepared a talk in which she was going to discuss functional aspects of self care. She was preceded by a physiotherapist who talked about the benefits of exercise on the underlying disorder. The physiotherapist recommended walking and low-impact gym work. Non-weight bearing activities such as swimming and cycling were frowned upon, as were high impact activities such as golf. The psychologist hoped that the church hall was not full of swimming, cycling or golf fanatics...”



4.2.1 Diaries

Keeping a more accurate record/dairy of the problem can enable the true severity of the problem to be established and identify patterns so far unnoticed. This in itself can be therapeutic.

A patient who says they never sleep might establish that they do in fact sleep six hours a day (four at night and two in the afternoon). The treatment might now be to reassure them that they are getting all the sleep they require and to encourage them to work towards taking the sleep all at the same time.

Diaries can be as simple or as complex as the patient is happy to keep - they do not need to restrict themselves to biological events but can also include thoughts, images, emotions as well as avoidance behaviour. The diary can also be used to test theories/hypotheses perhaps linking alcohol and smoking habits; menstrual cycle and mood changes; tablets taken and headaches etc.

Encouraging diaries and other homework can also:

- help demonstrate how committed people are to change and where they are in their change pathway;
- support the concept that change needs to be initiated by the patient, not the clinician;
- encourage the patient to interpret their own problems before the next consultation;
- decrease time needed for extended consultations and also allow records to be made at the time rather than trying to recall events that may have occurred several weeks ago.

Homework can include diaries, testing hypothesis, practicing a new skill, obtaining some additional information and analysis of thoughts/beliefs.



4.3 Goal-setting, pacing and planning

In order for people to gain control over the process of change, they need to be supported in the following:

1. Setting reasonable goals
2. Making a plan or plans towards reaching the goal(s)
3. Instigating the plan(s)
4. Checking progress at regular intervals of ability to follow the plan and whether plan(s) look if they are going to achieve the desired goal(s).
5. Making changes to the plan as necessary
6. Giving themselves rewards when goals are attained (attaining the goal(s) can itself be the reward)
7. Setting further goals

Goals should be reasonable. This is fundamentally important. Many people with long term conditions have not considered the need to change their lifestyle at all. Accepting that there is a need for change and for a recalibration of goals is a key initial step towards real, sustainable change.

4.3.1 Acceptance

Many people continue to live their lives, expecting themselves to be the person they were before the onset of their disorder or expecting health or social care to intervene in order for their lives to continue unchanged. Being continually unable to live up to this expectation can lead to worsening of symptoms, anger and frustration. Additionally, well-meaning clinicians can unwittingly collude with this unrealistic expectation unless acceptance and change are explicitly discussed.

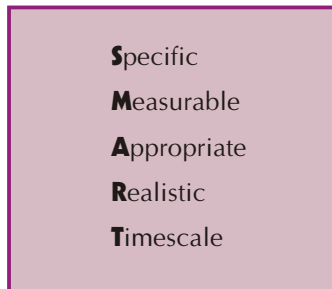
Helping people to construct reasonable goals involves asking them to consider a 'desired future self' that is attainable.

The distance between the expected future self (if behaviour doesn't change) and the desired attainable future self can be highlighted. This is, in essence, developing discrepancy that can motivate a desire to change.



4.3.2 Setting goals

The acronym SMART is helpful to remember in goal-setting.



Example - a lady wants to lose weight. Her goal could be:

- S** To lose one stone,
- M** I will weigh on the scales in local chemist
- A** I'm at least four stone overweight and this is not helping my blood pressure
- R** This appears realistic,
- T** Before next appointment with you, in eight weeks time.

To achieve this goal she needs a specific plan, again following the SMART acronym:

- S** I will not eat food or drink alcohol after my evening meal
- M** I will do this on five nights a week over the next eight weeks
- A** This is appropriate as it would help me to achieve my goal
- R** This is realistic; I think I can do this
- T** I will do this starting from Monday and continuing until I come back and see you in eight weeks time.

Whether the intervention works or not is not the point at this stage. This appears to be a SMART plan to achieve a SMART goal.

Once the plan has been agreed, the patient can be asked to predict any problems they foresee in achieving this plan. This is not tempting fate but might highlight that they are going to two weddings in the next fortnight which will make it difficult on those days to follow the plan; thus the plan can be slightly changed. It is more important at this stage that the plan is achieved rather than the goal, as this will increase self efficacy and allow for a step up of intensity of the plan if required.

Goals, not results

It is always preferable if the goal can be an action rather than a result. For example, the goal: *"I will never have another heart attack"*, may not be achieved. *"I want to reduce the risks of having another heart attack"*, can be achieved and is easily adapted to the SMART acronym.



4.3.3 Attaining the goals

A number of specific techniques can be helpful in supporting people to attain their goals

Define the goals

People work towards goals when they are of sufficiently high priority (see above). Physician directed goals are less likely to be attained than patient-derived goals. Importantly, people are more likely to attain functional goals if they are activities that are vital (ADLs) or self-defining activities.

A 69 year-old golfer with back pain is more likely to plan a rehabilitation programme on the golf course than in the local gym.

Define the functional baselines

Diaries can be helpful. Ask the patient to think about defining baselines for three to four activities in the first instance. ADLs or self-defining activities should be prioritised. Over several days, ask them to work out how much of each activity they can perform on average before symptoms become intrusive. This is their functional baseline.

Pacing - work within the functional baseline to gain control and confidence.

Many people anticipate symptoms in specific situations. This vigilance is often associated with anxiety and can become a learned response, leading to avoidance behaviours. Practicing the activity within the functional baseline (at 50% of the functional baseline) can lead to decreased anxiety and a greater sense of control. This can also lead to frustration, unless the pacing is associated with a planned programme to gradually increase the activity as confidence is gained. Pacing and planning are related to the following specific techniques:

Graded exposure

Gradual increased exposure to a stimulus can help people to control the resulting behaviour. For example in arachnophobia it can be gradual and start with the letters 'SPIDER', then a child's drawing of a spider, then a photograph, moving up to TV images and then a real live spider at different distances. It is expected that each step will cause an anxiety reaction in the patient which they need to tolerate for a time. If they can manage this, they learn that the symptoms triggered can be tolerated and controlled. The resulting behaviour can be avoided despite a feeling of dislike for spiders. This change in behaviour in turn often lessens the thoughts triggered by the spider.

The technique of graded exposure to external objects that trigger fear can be translated into graded exercise to overcome fear of activity.

Graded exercise

Graded exercise focuses on improving the patient's activity tolerance by progressing parameters (i.e. intensity, duration, or frequency of exercise). With graded exercise, the patient's reported symptom intensity does not limit exercise progression, and symptom abatement is not considered the primary intervention goal. {57,58}

Systemic desensitisation

This is similar to exposure but the patient learns relaxation techniques or distraction techniques to employ at the same time as they are undergoing graded exposure or activity. This can be as simple as suggesting that they listen to a favourite piece of music whilst undergoing their graded exercise or it can involve more complex interventions such as specific relaxation techniques.

Other specific behavioral techniques are detailed in section 5



SECTION 5

FURTHER SKILLS

These skills are not necessarily used in every consultation and many are easier to acquire than those mentioned previously.



5.1 Additional Counselling Skills

5.1.1. Paraphrasing

This involves picking up the meaning of the patient's words and putting it back to them accurately. You can use your own words and/or the patient's. Use a tentative, almost questioning tone, as if checking you understand what is being conveyed.

Patient: *"My wife told me to come and see you today but I'm not sure you or anyone else can help me."*

Doctor: *"So - you're not sure about being here, and whether help is possible from me or anyone else."*

If paraphrasing is done well it allows patients to hear their thoughts reflected back afresh. This often will allow them to view their thoughts from outside themselves which can help initiate the process of reconstructing any unhelpful thoughts that are present.

Another useful skill is to follow a question with a paraphrase, this prevents the consultation drifting into a question and answer session, where the patient simply answers the question then waits for another question.

5.1.2. Summarising

Summarising can be used for a number of situations:

- to check that you are both together in your understanding;
- to help focus on the main thoughts and feeling present in the last section of the consultation - especially important if the patient has just talked for a long period;
- as an aid to return to something significant;
- to keep structure to the consultation if the patient or clinician is getting lost;
- to act as a bridge for the patient to move on;
- to bring the consultation to an end.

Doctor: *"Thank you for explaining all the details. It seems to me that you know that your leg will take time to heal but the real problem is coping with work in the mean time."*

This can lead into different avenues:

"So, should we spend the remaining time today chatting about what we can do to help with work?"

"What is it that your leg specifically makes difficult at work?"

"I was wondering if work is difficult. How are you coping with three young children at home?"

A good summary enables the clinician to guide the consultation into any direction they feel is necessary.



5.1.3. Drop the why

Questions that begin with 'why' can be very threatening. The patient may become confused as to whether you are helping or challenging and might then try to justify their thoughts or actions rather than consider change.

Clinician: *“Why do you think you are depressed?”*

This is threatening and also vague. Is it asking why the patient believes that they have started to suffer from depression or is it asking why the patient feels that their group of symptoms is depression? The question could be rephrased: *“Can you describe the sort of events that tend to make you feel depressed?”*

5.1.4. Drop the but

The word 'but' is often used to join two thoughts together. However, the impression that this might give is that the initial thought is not correct. Look how much less threatening a sentence feels if you change the 'but' for an 'and':

*“I love my wife, **but** we fight too much.”*

*“I love my wife **and** we fight too much.”*

Rather than interrupting the patient to make this change, you can do it when you summarise. It's also important to restrict the use of the word 'but' in one's own phraseology:

*“This medication is excellent **but** very occasionally it can cause an allergic reaction.”*

“This medication is excellent. Very occasionally it can cause an allergic reaction.”

5.1.5. Change the order of a sentence

When a sentence has two parts as in the examples given above, it is always the last comment that remains in the consciousness for longer and thus is emphasized. It can be helpful to alter the order of the sentence to emphasize the positive. In these situations using 'but' can hide the initial negative comment.

*“I really enjoy dancing **but** my knee pain makes this difficult.”*

could be changed to:

*“I really enjoy dancing **and** my knee pain makes this difficult.”*

or:

*“My knee pain makes dancing difficult **but** I really enjoy it.”*

*“You have struggled to maintain weight loss in the past **but** have been excellent in your ability to lose it in the first place.”*



5.2 Other behavioural techniques

5.2.1. Reinforcement

This stems from the assumption that most behaviour is maintained by its consequences. Reinforcers tend to act like rewards for certain behaviour. Reinforcers have inherently different values to different people; a reinforcer for someone could be a punishment for another, for example. an outlandish hairstyle could create additional attention which could be desired by some and abhorrent to others. Reinforcement can be from outside (overt) or from within the patient themselves (covert). Patients often need to perform many unrewarded trials of behaviour resulting in no reinforcement before the behaviour is extinguished.

For a reinforcement to be successful it needs to be:

- Instant: any delay weakens the link between task and reinforcement
- Consistent: any expected reinforcement must materialise
- Significant: a reinforcement that the patient values
- Appropriate: size in keeping with task
- Specific: such as allowed to have an extra half pint of lager, rather than just allowed to have a rewarding drink

Remember if reinforcement is a complement, never give a complement then qualify it with a 'but', for example: *"but this would have been much simpler if you did it months ago."* As mentioned in section 'Drop the butts', ending with a negative statement will ensure the patient remembers the negative not the positive statement. The reinforcement is soon forgotten.

5.2.2 Prompting and cueing

The patient is taught to recognise early behaviour patterns at the start of anxiety attacks, or prior to an important meeting etc. They are then taught a cue word such as 'calm' or even an action: 'placing the thumb against the fourth finger and pressing' and this acts as a trigger for learned altered behaviour such as relaxation or distraction.

5.2.3 Modelling

This is when a new behaviour pattern is demonstrated to the patient, so that it can be shown that certain behaviours can work. If the model can be demonstrated in someone who is in the same peer group as the patient it will have more impact. It is also noted that people who achieve the model with difficulty (coping model), are often better models than those that make the task look very easy (mastery model).

Modelling can be done by a short role-play during a consultation. This can be as simple as suggesting opening lines when wanting to approach a boss about some change required at work, to dealing with a long job interview.

Modelling can also be done via videos, watching others around us or even specific characters in TV programmes.

5.2.4 Response cost

This is where a positive reinforcement is removed after the patient performs a certain unwanted behaviour or fails to perform a wanted behaviour, for example, the patient is stopped from watching television, or not allowed to eat pudding etc.

5.2.5 Differential reinforcement or other behaviour

This involves the patient reacting to a certain trigger factor by behaving in a way that makes unwanted behaviour impossible, such as having a shower immediately after a meal to prevent the post meal cigarette. An alternative could be going to the gym.

5.2.6 Chain control

As mentioned earlier the trigger event is often followed by a chain of events that finally ends with the unwanted behaviour. Steps can be taken to try and lengthen the chain of events or break the sequence. For example, keeping no chocolate in the house, so if you want a chocolate bar you have to drive to the local shop. Lengthening the chain might just make the reward at the end become less than the effort of achieving the goal; thus the behaviour will tend to stop. A word of caution is that the stronger the potential reward the greater the temptation to cheat or soldier on regardless of what obstacles are placed in the way. We have all seen smokers huddled together outside work buildings in the cold and rain to have that draw on a cigarette.

Patients are often very good at thinking about things they can do to help increase their own chain length. One used by a female patient who used to buy snack food was simple - to never carry any cash. Not surprisingly the snack trolley at work didn't take credit cards and her work colleagues were asked not to loan her money.



5.3 More about self efficacy

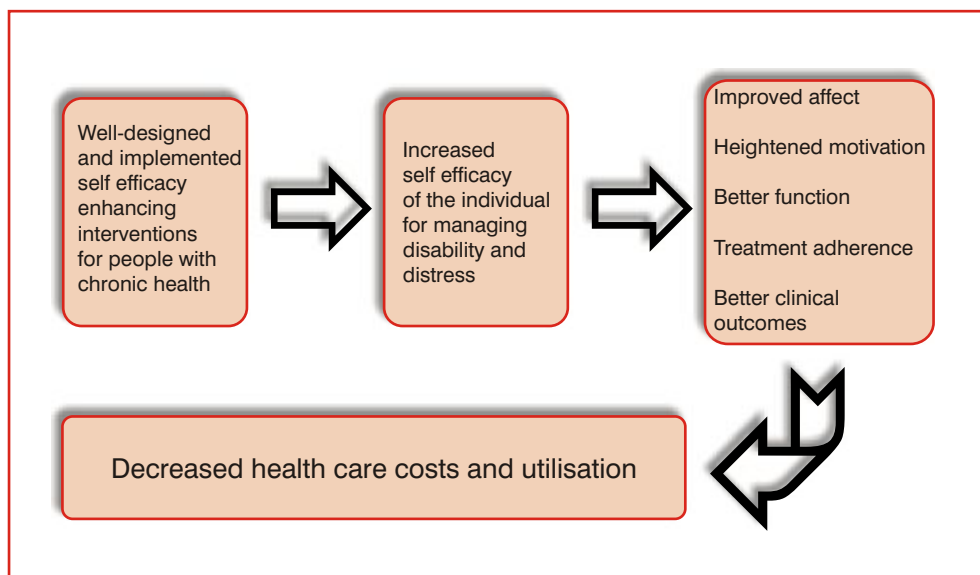
Self efficacy focuses on the individual's personal confidence/beliefs about their capacity to undertake behaviours that may lead to a desired outcome such as improved health.

Bandura (1996) identifies four ways in which self efficacy can be built:

- facilitation of skills mastery;
- exposure to, and sharing of, experiences of others;
- use of social and verbal persuasion by others deemed knowledgeable about the activity
- drawing attention to the individual's physiological and affective state prior to and following the desired activity.

Learning from the experiences of others

Clinicians can do this by relaying information about other patients and there are also a large number of groups where this is done excellently. The expert patients' group is particularly good at this task, but there are also a number of disease specific groups, and internet chat rooms, etc.



Hypothesized model of effects of self-efficacy enhancing interventions for people with chronic disease - Marks R; Allegrante J.P and Lorig K - Health Promotional Practice April 2005 VOL.6 No.2. 148-156. 'a review and synthesis of research evidence for self-efficacy enhancing interventions for reducing chronic disability: implications for health education practice (part II)

How to assess self efficacy when writing plans

When you have agreed a provisional plan with the patient ask the patient on a score of (perhaps 0-10), how likely they think they are to achieve this plan. This is simple assessment of self efficacy.

The magic number is seven. If the patient scores the likelihood of achieving the task as seven or higher then stick to the plan.

If the score is below seven then, if possible congratulate them on not scoring it at zero and ask what aspects of the plan they do feel able to complete (reinforcing the positive aspects) Then ask why does the patient score it so low, - what problems do they foresee? If the problems can be avoided or minimized, ideally by the patient themselves, then you can score again. If the score is still below seven the magnitude of the task needs to be reduced until the score is above seven. If the scores remain permanently low it is worth thinking about specific self efficacy enhancement before returning to the plan. It might also be that the patient is not ready or willing to make the change (see section 2.2.2 The readiness to change) .

5.4 Locus of control

In order for any patient to efficiently self-manage, they must remain within their locus of control, both within and between consultations. It is easy to fall into the trap of taking control or passing the control over to the medical condition itself (i.e. *"You can exercise as long as your blood sugars are OK . . ."* this places the diabetes in control. *"You must ensure your blood sugars are under control before you exercise . . ."* here the control is with the patient).

The locus can be kept with the patient, by:

- working at their rate;
- asking them what actions should be taken;
- making suggestions to treatment ideally with the choice remaining with the patient;
- taking the issues that the patients perceives as most important;
- educating the patient in areas where necessary to allow them to remain in control and make decisions (help them to make as informed a choice as the patient wishes to make).

Occasionally it is necessary to make alterations to the patient's medication or order additional tests. They do not necessarily have sufficient medical knowledge to be able to make a fully informed choice. This is always a difficult situation but needs to be handled carefully. Try to explain your actions in terminology that the patient understands and addresses their value/belief system. It is unrealistic to expect a patient to understand why each of the specific auto-immune function tests have been asked for (many doctor struggle with this area), but it is fair to explain why you think further investigations are necessary, then allow the patient to consent or not.



5.5 Consultation contracts

Setting a contract for consultation - if there is something specific, agree when this is going to be tackled during the consultation. This contract needs to be an amalgamation of patient and clinician agendas, and needs to be mutually agreed, allowing for the limitations present, such as time and expertise.

Although we must follow the patient's agenda, occasionally you will have information that the patient is not yet informed about. Under these circumstances the patient's choice is not fully informed so you have some justification in leading the plan in another direction. For example: let us suppose you have just received a liver ultrasound showing multiple metastatic deposits: *"I think talking about your smoking is very important but can we come back to this at the end of the consultation, first I would like to chat about some of the results we have received back from the hospital."*

I allow patients to make appointments for variable lengths in ten minutes sections according to their own wishes, for example 10,20,30, 40 etc. By doing this I'm allowing the patient to self manage me as a resource but in return they take ownership of the time available. If we run out of time because issues took longer then they allowed, they are responsible. In theory this could lead to them over-booking me to always ensure they have enough time, but in practice I can only remember this happening twice in the last ten years. They appear to appreciate my time as a resource that should not be used up all at once.

5.6 Why people procrastinate

It is important to try and understand that motivation doesn't come first, productive action does. Often you need to get started whether you feel like it or not, but once you have begun and start to see some accomplishment, it is likely to spur you on to do even more.

The above demonstrates why many people never achieve certain tasks (like putting the photos in the photo album) as they tell themselves: *"I will wait until I feel like doing it."*

Another problem with procrastinators is they might think that life should be easy and that others don't have to struggle. If this belief is held patients will most likely conclude something is wrong and give up when the going gets tough. This may also lead to frustration and resentment.

If you assume that an activity will be very hard, and at times frustrating and will include setbacks along the way, then when these obstacles are encountered you are much more likely to persist.

Fear of failure is another common reason why someone might procrastinate, and hence become stuck in the contemplation stage of the cycle of change (see section on cycle of change).

This can be addressed in two ways:

- initially by minimizing thoughts of failure by enhancing self efficacy (see section on self efficacy);
- exploring what actually will be the true impact if they fail, this can be done by a technique often called the 'vertical arrow'.

In the vertical arrow technique you start by writing down the consequence that the patient expects to happen. A vertical arrow is then drawn down from this statement symbolising the sentiment: *"So if this was true - what would this lead to."* This sequence often leads to a rather benign end point, defusing the fear of failure.



5.7 Cost-benefit analysis

This is a technique for the patient to evaluate if a specific change is right for them according to their own value system, not those of their clinicians.

One method is listing all the advantages of making a change against all the disadvantages of making the same change. For example: Rosemary is not sure if she wants to stop smoking:

Advantages	Disadvantages
I would feel better and less short of breath	I find the smoking a good way to deal with stress
My cough is likely to eventually settle	Being a smoker I get an extra break at work
I would save a lot of money	If I stop smoking I might put weight on and this might make me feel unhappy
It might save me from developing lung cancer or emphysema	It is likely to be unpleasant for both myself and my family as I go through giving up
It would stop my children passive smoking	Smoking is a sociable thing to do with my friends, if I stop they might think I no longer fit in their group
It would make me a better role model for others especially my children	
To actually stop would give me a great feeling of achievement	

These thoughts contain some dysfunction (see unhelpful thinking section) and it is often sensible to re-write these thoughts before trying to move on, but for this example I will let the initial thoughts ride.

The next stage is to give every thought a score between 0-100 as to how important this factor is:

Advantages		Disadvantages	
I would feel better and less short of breath	15	I find the smoking a good way to deal with stress	20
My cough is likely to eventually settle	30	Being a smoker I get an extra break at work	20
I would save a lot of money	10	If I stop smoking I might put weight on and this might make me feel unhappy	80
It might save me from developing lung cancer or emphysema	85	It is likely to be unpleasant for both myself and my family as I go through giving up	70
It would stop my children passive smoking	95	Smoking is a sociable thing to do with my friends, if I stop they might think I no longer fit in their group	65
It would make me a better role model for others especially my children	45		
To actually stop would give me a great feeling of achievement	30		
Total Advantages	310	Total Disadvantages	255

The advantages outweigh the disadvantages and the change seems to make sense based on Rosemary's own belief system.



5.8 Two common problems

People can become disillusioned if they fail to accomplish a plan or if the plan fails to achieve the desired goal. If they failed to achieve the plan, then the question is for the patient to ask themselves if they did their best. If they honestly did their best but still failed, they should have a clear conscience, as no one can ever do better than their best.

This does not mean that the plan will never be achieved it just means that the plan must be made easier (stepped down). Once this lower step has been achieved, they can then increase the steps up towards the original plan with each completed step their best will most likely get better.

Another problem is one of an overactivity/rest cycle. If the patient is over motivated, or too impatient to take small gradual steps, they might start a new plan with too much vigour. A common example is someone who takes up a new activity, but after a week has pushed themselves too far and fast, to the point that they have injured themselves then have to avoid all exercise for several weeks to let the body recover. I often say that when starting a new exercise if you are not embarrassed by how little you are doing you are probably doing too much.

5.9 Enjoy the journey

Many people often believe attaining goals is the key to happiness and life satisfaction. They must get what they want in order to be happy. This is a very oppressive way of living as it implies existing in a constant state of deprivation. Trying to be happy by achieving goals is living in a world where what is important is constantly missing. This might create motivation for change, but can ensure the journey (the time spent achieving this goal) is hated and that unfair expectations are placed on the goal should it be obtained, leading to a more rapid relapse. This is fundamentally a confusion between goals and values.

“Creating a goal is the process by which the process becomes the goal.”

The journey for our patients is one that we must take with them, from their present selves to their future selves, once this has been adjusted for their medical long term condition. This journey can take a week, month or a lifetime so it is imperative to enjoy the journey.

Once the future self is reached most people want to go on and achieve a new future self, hence starting another journey.



APPENDICES



APPENDIX 1

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APPENDIX 2

Consultation overviews

1.1 The unspoken agenda

People who consult clinicians have a number of questions that they want answered, particularly:

1. What is it?
2. Why me?
3. Why now?
4. What can you do about it?
5. What can I do about it?

Some of these may have already been answered, so clinicians might let themselves be directed to answer the questions still outstanding.

This framework can also be used to assess what the person with any long term condition already understands about their condition.

1.2 Consultation in detail (for primary care)

This section is designed to be of particular use to the less experienced clinician.

Discover the reason for attendance

The presenting complaint - encourage the patient to talk with verbal and non-verbal support

Obtain more details about presenting complaint

History of presenting complaint - what is the patient's agenda and expectation from the appointment?

Set contract for consultation

Outline clinician's expectations for the consultation - invite input from the patient on their expectations, and reach an agreement.

Specific enquiry

This needs to address the three areas of the biopsychosocial model.

Biological - The biological model requires a standard history asking specific biological based questions to try and identify the nature and severity of any biological process.

Social - Is often easiest to tackle next. Put the presenting complaint into context for both the patient's social and occupational life: *"The pain in your back sounds very unpleasant are you able to still work?"*, *"What else are you finding difficult to do at present?"*, *"What impact is this having on the rest of your life?"* It is also very helpful to try and identify expectations for the future at this stage such as wanting to get a promotion or a return to work.

Psychological - Try to understand the thoughts/beliefs behind the reported symptom (the presenting complaint might be an ache in the right eye and the belief could easily be: *"I'm going blind I'm following in my Gran's footsteps and developing glaucoma."* This can often be achieved by asking the patient: *"What are you worried the cause might be?"* and: *"Are you worried what it might lead to?"* patients will normally be very happy to express these concerns.

Appropriate physical examination

The examination can be therapeutic in itself and also needs to be done in context with the patient's own thoughts/beliefs. For example if the patient presents with a classic story of otitis externa but thinks the pains are referred from the heart, it is sensible to examine the heart even if you have already found the otitis externa. This shows you are taking the patient's beliefs and value system seriously and builds on their ability to self manage in future as it demonstrates you are happy to let the patient have some control over your role and to use you as a resource to meet their needs. It is important to explain what each aspect of the physical examination is designed to identify as the examination progresses, and to reassure as necessary.

Explain findings

Use language appropriate for the patient and specifically address their beliefs and expectations.

Consider hidden agendas

Do you think there is a hidden agenda? Perhaps you feel the patient still isn't prepared to express their true thoughts and worries yet. You can try to gently ask again, but if this meets resistance it could mean that you are wrong and there is nothing hidden, or that the patient still doesn't want to share that much at this stage. By continuing with the consultation you will develop the therapeutic relationship further and this will help. That is why so many hidden agendas come out at the end of the consultation once patients have established they can trust you.

If this happens you will need to assess whether the problem needs to be dealt with now and hence run late, or whether you can agree that this is a very important area that needs addressing but that time constraints mean they will have to return to give it the time it deserves (this is a problem most clinicians are very used to dealing with).

Summaries - include a working diagnosis (if possible)

"It sounds as if you are getting more angina recently, which is worrying you and limiting your ability to exercise, as a result you are gaining weight."

"You appear to have lost a lot of weight recently, and you're not sure if it is related to working longer hours or if you might have something else wrong especially as your mother developed bowel cancer at roughly your age. Well, after examining you and listening to your description of what is happening I think it is more likely to be related to your job, and lack of healthy eating. How would you feel if we carried out a few investigations to confirm this?"

Agree a management plan - overview - all three domains (biopsychosocial)

"It seems to me that there are a number of areas we need to cover. First if we could make you less short of breath, that would be good - we could try some changes to your medication. Secondly, you seem very worried about being breathless and fear that your heart is getting worse. This is not necessarily the case and perhaps we could spend a few minutes today talking about this. Thirdly, work is clearly getting quite difficult to manage, perhaps we could think about this together. Does that sound OK, or is there something else that you would like to spend the remaining time today on?"

It is quite acceptable to address only one or two areas now and to address the remainder at a further consultation. Just being told that all three areas are going to be addressed can be a significant relief and therapy in itself.

Instigate self management of biological domain.

For a patient to be able to self manage their biological condition they need to understand what is causing the symptoms, what treatments are available and when to use them. They also need to know how to monitor the success and safety of treatments.

For most long term conditions this is a large task. Most patients already have some knowledge, but it is important to check they are correctly informed. There are a vast number of self help books, leaflets, and groups available which tackle the biological problems very well, and it might only be necessary to direct them towards one of these additional resources. It is important to ensure that they have enough understanding to make any changes to treatment that you might be suggesting today.

To promote self care, it is often helpful to outline a very simple management plan, such as:
“Try taking this new tablet called frusemide once a day in the morning, which as I have just explained may well remove some of the fluid that is adding to your breathlessness. If after being on the tablet for a week you are not feeling any better, increase the dose to two tablets of frusemide in the morning. If after another week you are not getting any better come back and see me, but if one or two tablets help, remain on that dose and come and see me in four weeks.”

It can be helpful to write this plan down if you are not convinced the patient will remember. This is a very simple example of self care. You have given the instructions and ensured the management is maintained within safe limits but the locus of control moves from the doctor to the patient.

Side effects and ways of monitoring treatment also need to be discussed, as should warning signs:
“If your breathlessness is getting worse do not wait the full four weeks; come back and see me sooner.”

If investigations are necessary this can also be structured in a self management way to try to help the patient gain a sense of control: *“Here is a blood form so we can check that your thyroxine levels are correct. There are the times when the blood taking services are available, no appointments are necessary you simply turn up on what ever day suits you and wait your turn. It would be helpful if you could have the blood test and come back to see me one week after having the blood test so we can chat about the results.”*

Instigate self management of beliefs or unhelpful thoughts.

Address their beliefs about their long term condition/symptoms. Many people will have developed misconceptions (mistaken beliefs) about their condition, their prognosis or the role of health or social care in providing care, cure or support.

Try and establish exactly what the patient understands about the diagnosis. What the cause of the symptoms are, and what the future is likely to hold. Most primary care physicians can do this very rapidly using previous knowledge of the patient and family. Being in a trusted position, directly challenging the patient about beliefs is often acceptable:

- establish beliefs;
- if not true, challenge by giving an alternative model for consideration;
- look for any unhelpful thinking. If present, try and identify the unhelpful thought and agree a new more accurate thought;
- employ various strategies (cognitive reconstruction) to support the development of more helpful thoughts.

Instigate self management of social issues

It is also necessary to explain that best evidence biological disease and symptom management is being delivered, but this is unlikely to be enough by itself. Most patients will already have first hand experience of this and may well volunteer the information if prompted.

To address social issues a number of tools are helpful. These are mentioned in greater detail elsewhere in this book, but in brief overview:

- establish what the patient wants to achieve (future self);
- establish if this is realistic. If not, help determine new future self by agreeing activity goals;
- If change is necessary to achieve the future self, encourage the patient to accept this and that they are responsible for the change, but that support will be available to facilitate the process;
- agree what change(s) will be tackled first;
- establish where the patient is on the cycle of change, and then facilitate the patient's journey to the maintenance stage of the cycle.

GP issues

Quality points, health promotion, etc

Practice issues

Address any area of necessity to the practice, such as confirmation of address details, information about how to make appointments, etc

FRAMES

Plans and agreed follow-up. FRAMES is described elsewhere and is an excellent way of bringing the consultation to a natural end on a positive note. When FRAMES is used at this stage in a consultation it can be combined with appropriate vocal tone and body language to indicate that the consultation is ending.

Review your own personal issues prior to next consultation.

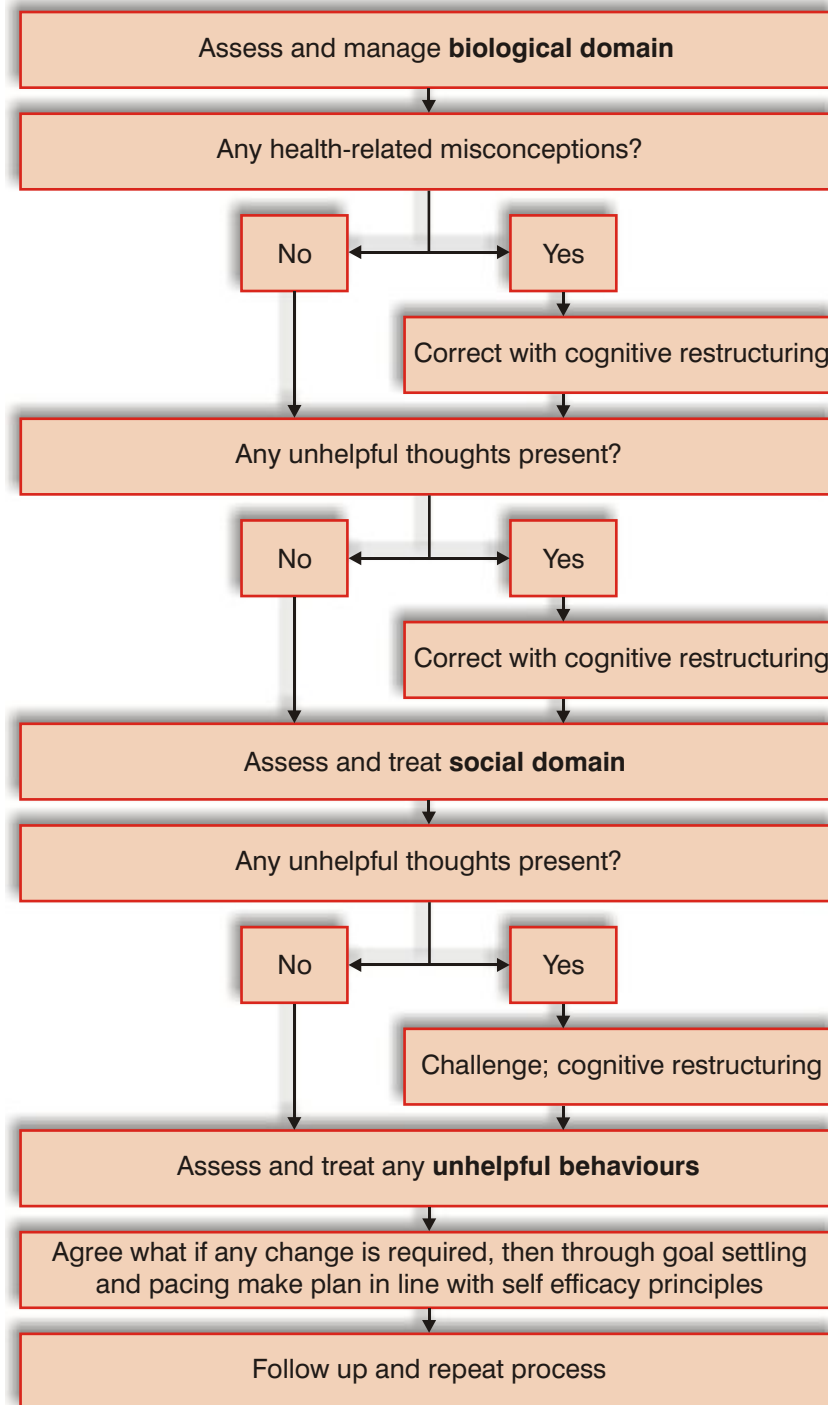
Ensure that all activities you have undertaken to do are recorded to ensure you do not forget to do them. Then you need to ensure that you are able to deal with any emotions that have been triggered by last consultation and are fit to start another consultation.

This consultation will most likely take more than the allotted ten minutes, but the sections: 'Instigate self management of thought' and 'Instigate self management of social issues' can be tackled to a variable degree dependent on time and, as mentioned earlier, most patients are happy to return for this further review.



APPENDIX 3

SAMPLE PATHWAY





APPENDIX 4

Evidence that self management works

If you have five minutes this section is really worth reading to fully understand the strength and breadth of the evidence.

General evidence

- Instigating a self management programme has been shown to reduce follow up visits to general practitioners by up to two fifths {2, 3, 4, and 5}.
- Self management courses may reduce visits to all health professionals by up to 80% {6, 7}.
- A US study {8} found that self management programmes were associated with improved clinical outcomes for people with many types of long term conditions. After one year, participants had improved health status and fewer visits to the emergency department.
- Self management is not just giving out leaflets. It has now been clearly shown that although knowledge is necessary, it is often not sufficient alone for behavioural change. {9, 10, 11}

Self efficacy

A community based self management programme involving 551 people with heart disease, lung disease or type 2 diabetes, showed participants had better health status, health behaviour, and self efficacy and fewer emergency department visits compared to those receiving usual care. These improvements were maintained after one year. {13}

Social support and self management education were associated with reduced feelings of helplessness, increased self efficacy, and increased overall health status. It also reduced healthcare costs relative to controls. The author concluded that monetary savings from the interventions greatly outweigh their cost. {14}

A community based, nurse-led study showed improvement in disability, resourcefulness, self efficacy, behavioural, and life satisfaction among people with chronic pain. {15}

In a randomised trial self management courses increased participants' self efficacy, knowledge, symptom management, use of self management behaviours, and aspects of health status. {16}

A self management programme in an under-served, poor, rural population still found significant improvements in self efficacy, and self management behaviours. {17}

Biopsychosocial approach

The concept that mental states are influenced by many interacting processes, such as bodily processes, personality dispositions and life events, is a very old one. It was well articulated by the early Greek physicians over 2000 years ago {18}

Gilbert concluded in his paper: 'Understanding the biopsychosocial approach: conceptualisation.' {18} that one thing is clear - although many clinicians of all types pay lip service to a biopsychosocial approach, few adopt it in their clinical practice or research. The main reasons he draws for this are that clinicians do not understand it and it calls for radical shifts in research, training and practice.

Behavioural change

Behavioural change is the most successful outcome as assessed in a review of self management interventions. {19}

Quality of life and satisfaction

A review of self management programmes showed a tendency for people to report reduced severity of symptoms and pain, and improved life control, activity, resourcefulness, and life satisfaction. {20}

Diabetics showed a clear improvement in quality of life. But this effect took a long time to develop but was still present at four years. {21}

Self management can work for everyone. A study from 2004 showed self management improved satisfaction with care in a cognitively impaired group. {22}

Overview evidence

In a review of evidence for self management in adults with type 2 diabetes, asthma, rheumatoid arthritis, or osteoarthritis; self management interventions were generally shown to be beneficial across a number of biological and psychological areas. {23}

A systemic review of 71 self management education trials for people with long term conditions showed that people with diabetes participating in self management education had improved glycaemic control and blood pressure. People with asthma experienced fewer attacks after self management education. {24}

A small randomised trial with a follow-up telephone call and newsletters found that self management improved the use of community resources, physical activity, and adherence to medication. {25}

A UK based randomised study over five years involving over 100 patients showed that chronic disease self management programmes were associated with improved healthy behaviours, coping, communication with physicians, self-reported health status and reduced days in hospital. {26}

Specific conditions that benefit

Asthma

A self management programme in Hong Kong showed reduced hospitalisations and reduced the length of hospital stay by up to half. {27}

A review of self management in the Lancet showed 57% of self management intervention programmes showed improvements in lung function. It also concluded that stress and emotions management as well as behaviour can be successful in improving lung function in asthma. {28}

Self management education reduced hospital re-admissions threefold for adults with asthma. {29}

A brief self management programme while in hospital for asthma reduced re-admissions and morbidity. {30}

A review of 32 randomised trials, in patients aged two to 18 years, showed self management education was associated with improved lung function, reduced absenteeism, reduced days of restricted activity and visits to accident and emergency departments. {31}

In this study that was delivered by GPs, community nurses and asthma nurses, who taught self management skills to patients less than five years old; it was found that patients had more knowledge, a favourable attitude towards asthma, higher competence in asthma self management and less doctor visits after the programme. {32}

Three months after a self management programme, participants had better knowledge, adherence, and self management behaviours compared to controls. There was some suggestion that a maintenance programme might be required to sustain this benefit. {33}

Inflammatory Bowel Disease

Consultants were trained to provide a patient-centred approach to care, not even a full self management tool kit. Guidebooks on Ulcerative Colitis (UC) and Crohn's Disease were developed with patients prior to the study. Patients prepared written self management plans and referred themselves to health services based on their own evaluation of their need for advice. After one year, the self management group had fewer hospital visits, but there was no change in the number of primary care visits. Patients felt more able to cope with their condition. Cost effectiveness analysis favoured self management over usual care. {34} (Primary care was not instructed in patient-centred approach and the role of the guidebooks).

In patient-centred self management training and follow up on request or usual care for patients with UC, self management training was associated with faster access to treatment when needed, reduced hospital visits (0.9 versus 2.9 per year) and fewer GP visits (0.3 versus 0.9) per patient per year. The authors concluded that this approach may be feasible in long term management of many other chronic conditions. {35}

Depression

Self management courses increase participants' self efficacy, knowledge, symptom management, use of self management behaviours and aspects of health status (such as depression {36}

Diabetes

Self management education in community settings for adults with type 2 diabetes improved glycaemic control {37}

In a community self management programme involving people with heart disease, lung disease or type 2 diabetes, it was shown that participants had better health status, health behaviour, and self efficacy and fewer accident and emergency department visits compared to those receiving usual care. {38}

Using study educational interventions showed improved knowledge, self care behaviour, and metabolic control in adults with diabetes. {39}

A review of self management interventions showed evidence of improvements of HBA1c (Glycosylated Haemoglobin). {28, 40}

Like previous review studies, this study showed evidence of improvement of HBA1c (Glycosylated Haemoglobin). These effects are often sustained {41}

Thirty-one randomised controlled trials, showed improved glycaemic control, compared with usual care. {42}

DAFNE (Dose Adjustment for Normal Eating) which is a limited self management programme was shown to improve quality of life, satisfaction with treatment, and reduced blood glucose levels. {43}

Hypertension

A Chinese study looking at hypertensives showed improved awareness about the condition, reduced risk factors, reduced visits to the doctor, and improved health status {44}

Chronic Obstructive Pulmonary Disease (COPD)

In Canada a study looked at patients with COPD. It involved weekly visits by health professionals over a two month time period, with monthly telephone follow-ups. Self management education was associated with 40% fewer hospital visits for COPD and 57% fewer hospital admissions for other problems. Emergency department visits reduced by 41% and unscheduled clinician visits by 60%. {45}

Self teaching can be as effective as group sessions in patients with COPD. These findings are likely to apply to other conditions. {46}

In a study in Norway on self management for COPD, self management reduced GP visits by 85%, reduced reliever medication use, improved patient satisfaction with the care provided by their GP and reduced the overall cost of care over a 12 month period. {47}

Ischaemic Heart Disease (IHD)

A home based cognitive-behavioural, self management rehabilitation programme for myocardial infarction patients reduced re-admissions by 30% {48}

Cardiac rehabilitation delivered along self management principles leads to improved lifestyle, reduced hospital re-admissions; improved return to work rates, improved health related quality of life, reduced blood pressure and cholesterol levels, improved patient knowledge and psychosocial well-being. {49, 50}

A Cochrane review found that in 48 random controlled trials, cardiac rehabilitation results in a 20% reduction in all cause mortality and a 26% reduction in cardiac mortality at two to five years. {51}

A weekly self management education programme led by a health educator and peer tutor improved physical functioning and symptoms in older women with heart disease. {52}

Depression after Mental Illness

Depressive syndromes are associated with an increased cardiovascular risk. A study published in 2004 showed significant reductions in anxiety and depression scores in patients through completing a three week rehabilitation course. {53}

Pain

A randomised community-based study on self management showed improvement in disability, resourcefulness, self efficacy, behavioural, and life satisfaction among people with chronic pain. {54}

Arthritis self management education programmes tend to result in small reductions in pain and disability. {55}

Lower Back Pain (LBP)

Vlaeyen suggest a three step process for patients with LBP:

- 1) Screening for patients with elevated fear-avoidance beliefs
- 2) Educating patients with elevated fear-avoidance beliefs in a specific manner
- 3) Prescribing exercise that directly addresses the patient's fear and avoidance behaviour. {56}

Graded exercise focuses on improving the patient's activity tolerance by progressing parameters (i.e. intensity, duration, or frequency of exercise). With graded exercise, the patients reported symptom intensity does not limit exercise progression, and symptom abatement is not considered the primary intervention goal. {57,58}

Psychological consequences (such as exaggerated pain perception) and physical consequence (such as 'disuse syndrome' [loss of muscle force, and weight gain]) are associated with an avoidance response. {59,60}

This study supports the idea that patients should be educated in a way such that the patient views his or her pain as a common condition, rather than as a serious disease that needs careful protection. {60}

Heart failure

A randomised trial showed that participants in three sessions of self management education on heart failure who then adopted self management strategies were at lower risk of death and readmission to hospital. {61}

Arthritis

Self management had been shown to reduce pain and fatigue, improve activity levels, aerobic capacity and exercise endurance, reduce levels of disability and functional limitations and improved self-reported health status. {62}

Patients feel more confident and able to manage and control their symptoms - they tend to feel less anxious about their disease and visit the doctor less frequently. This is based on 'Challenging Arthritis' a self management course used by UK's Arthritis Care. {63,64,65, and 66}

In 25% of studies reviewed there were reduced numbers of painful and swollen joints following a self management course. {19}

Other systems

There is now considerable evidence that, from the day we are born, the quality of our social relationships has a major impact on a host of physiological systems, including cardiovascular, immune and hormonal. {67}

So it works, is simple and fun, patients and clinicians enjoy working with self management, it is cost effective and the effects last - so why not give it a go?



APPENDIX 5

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