CBT for Chronic Illness and Palliative Care

A Workbook and Toolkit

Nigel Sage
Michelle Sowden
Elizabeth Chorlton
Andrea Edeleanu

John Wiley & Sons, Ltd

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Section 3: Record Forms

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Acknowledgements

This book grew from material prepared originally for a training project for staff working in either palliative care or with cancer patients in other settings. The authors gratefully acknowledge the vital contribution of Surrey, West Sussex and Hampshire (SWSH) Cancer Network, in sponsoring that training project.

We would also like to acknowledge the enormous influence on the content and structure of this book of Drs Stirling Moorey and Kathryn Mannix. Stirling has done so much to establish the role of Cognitive Behaviour Therapy (CBT) in the fields of oncology and palliative care that it is rapidly becoming a service requirement and many health professionals are now seeking some training. For us, his work at St Christopher's Hospice has been especially important because, along with the training project in Newcastle led by Kathryn Mannix, it has shown that staff with no background in mental health work can acquire and use cognitive behavioural skills. This has provided the inspiration for our own training programme and ultimately this book. Kathryn has also offered us encouragement and practical guidance with our training project for which we are very appreciative.

Grateful thanks are extended to Joanne Coombs for her help in preparing the chapter on the effectiveness of CBT to Ann Hatch, whose experience and skills as a physiotherapist have influenced numerous items included and to Maralyn Sage for her tireless work and patience with both the book and the training project that preceded it. A special thank you is also due to all the participants from our training courses who have taken the trouble to provide constructive feedback and persuaded us to publish. Their suggestions have enabled us to revise our course materials and make this a better book. In this regard a particular mention must be made of Maureen Adam and Susan Kobler who in dual roles as participants and seminar supervisors regularly provided ideas for improvements.

Finally, we wish to express our debt of gratitude to all the patients who, by sharing their experiences with us, have spurred us on to write this. We hope that the resulting book contributes to more people getting more help sooner.

Introduction

CBT in Chronic Illness and Palliative Care: A Workbook and Toolkit is divided into three parts and is intended to give the reader grounding in the principles and techniques of Cognitive Behavioural Therapy (CBT). Ideally, it should be used in junction with a taught course on the use of CBT with people who have life-changing illness or are terminally ill. The course will offer the opportunity to discuss working with these patients and the people close to them. It will give the student the chance to practice the skills they are learning through role-plays and small group exercises; and it will provide time for going back over material that has been difficult to understand or has been misunderstood.

However, such courses are rare, so the book has been written with the expectation that many readers will be learning these skills without the benefit of a supportive course. With this in mind, there are a number of exercises included that have been adapted from the courses we have run and we would ask you to follow these through very carefully if you intend to apply CBT skills in your clinical practice.

Part 1: The Workbook examines important issues and themes that need to be understood and considered by clinical practitioners as well as the basic principles of the cognitive behavioural approach. These range from wider aspects of behaviour change through to the specifics of assessing psychological needs. This material, together with key reference books and supplemented by the exercises at the end of each chapter represent the knowledge base for these core skills when applied to people with life-changing illness.

In **Part 2: The Issues** some psychological problems, obstacles and needs are referred to as "Problems". Relevant techniques and sample tactics are identified, providing an idea of how these CBT methods are applied in practice with each problem. Issues about implementing these procedures are covered in "Notes". Although not written in chapter format, close familiarity with the contents of this part of the book is extremely important.

Inevitably the selection of sample problems is far from comprehensive but the range is sufficiently wide to illustrate the scope of CBT usage. Consequently, when considering applying CBT methods, this part of the book should be consulted first. The intention is to give enough material for you to be able to:

- assess the problem or need
- indicate the typical cognitive-behavioural approach to coping
- where relevant include educational material that can be copied and passed to patients, carers or others
- assess improvement and need reduction.

Part 3: The Toolkit provides information on CBT methods in practice that may be of practical assistance when you are seeking to offer some help. There are plenty of different ideas for managing challenging psychological situations in the CBT literature and so, like the list of problems and needs, the suggestions for methods of helping included in this book could not claim to be exhaustive.

Part 3 is divided into three sections.

A fuller description of how to implement each CBT technique is provided in **Section 1: Techniques.**

Section 2: Information sheets includes further detailed guidance and information sheets which may be copied and used to assist in the CBT.

Section 3: Record forms provides methods for recording events, thoughts and plans in conjunction with the CBT techniques. These forms may also be photocopied.

A4 versions of all information sheets and record forms can be downloaded from the website free of charge and without copyright restrictions by owners of this book, for their own clinical use only.

PowerPoint slides for personal training are also available to view at the website.

PART I

The Workbook: The Cognitive Behavioural Approach

Chapter 1

What is the Cognitive Behavioural Approach?

Cognitive Behaviour Therapy (CBT) has been described by the pioneer of this therapy as:

> An active, directive, time-limited, structured approach.
>
> (Beck et al., 1979)

The therapy works by helping patients to:

> Recognise patterns of distorted thinking and dysfunctional behaviour. Systematic discussion and carefully structured behavioural assignments are then used to help patients evaluate and modify both their distorted thoughts and their dysfunctional behaviours.
>
> (Hawton et al., 1989)

With the cognitive behavioural approach there is recognition of the way in which all our responses are part of a complicated interplay of actions and reactions. In physics we accept the general law that every action produces a reaction. What is not always so well appreciated is that this applies in psychology too.

We are generally aware that our actions have effects on those around us as theirs do on us. The simple act of smiling at someone when they look at you will produce a reaction in that person. Perhaps they will smile back, treating it as a simple greeting; alternatively, they may interpret it as an invitation to come over and chat; under other circumstances their reaction may be one of anxiety or hostility, if they think you are laughing at them. What ever it is your action will produce a reaction, and that reaction, in turn will have an effect on you. Even a "non-reaction" (such as no glimmer of acknowledgement that you smiled) will carry *meaning* and provoke a specific reaction in you.

So our social environment affects our behaviour and our behaviour affects our social environment. To a greater or lesser extent the same is true for our physical and economic environments. We can influence (if not control) our comfort, wellbeing, affluence and future prospects. Our comfort, wellbeing, affluence and future prospects similarly can and do influence how we think, feel and behave.

From the cognitive behavioural perspective, however, it is the loops of cause and effect *within* ourselves that are of special interest. When I put my hand too close to the fire, the outside world (*external* environment) of intense heat sends signals of pain to my body's sensory receptors. From that point forward there are a series of reactions and interactions relating to my *internal* environment. The physical sensation of painful heat triggers emotional responses of intense dislike and thoughts of dangers to be avoided. But the most important and immediate reaction is a behavioural response of withdrawing my hand from

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the heat. Once this behaviour has happened, I experience a relief of the pain, my thoughts turn to labelling the hot object as something to be avoided or treated warily and it has acquired a negative emotional association.

So, in this example physical sensation has evoked a specific behaviour, reappraising thoughts, and an unpleasant emotional reaction. But these four elements (**physical sensation**, **behaviour**, **thoughts** and **emotions**) can interact in different sequences.

Let us take another example:

Jenny plans a picnic and is looking forward to it; then, on the day, it rains. If this event leads her to **think** "my day is ruined", then the **emotional reaction** will be as downcast as the weather, **physically** she is likely to experience a loss of energetic enthusiasm and her **behaviour** is likely to become restless and aimless. On the other hand, if the rain leads Jenny to **think** " I'll need a new plan for today", then any **emotional reaction** of disappointment will be tempered by **thoughts** about what else she can do with the day; this will produce a **physical response** of increased energy for planning and a series of **behavioural actions** around sorting out an alternative arrangement.

The *meaning* Jenny attaches to the event (that is, the way she thinks about the rain) determines her emotional, behavioural and physical responses and ultimately, therefore, the outcome for her of this damp day.

When it is a one-off event of only minor consequence, like Jenny's rainy day, then the effect of the way the event is interpreted is of no particular significance. However, when various events are lumped together in a single category and the same meaning is attached to all of the events in that category, then a pattern is emerging which is of greater influence in the person's life. It can be very helpful to us at times to have categories to put things into and sets of beliefs or attitudes to which we regularly refer. But sometimes the categories and attitudes can prove problematic.

Once again an example may help illustrate the point:

John **thinks** he makes a fool of himself whenever he introduces himself to other people. Because of this his **behaviour** is to hang back and try to avoid having to do it. The **emotion** that this produces is one of acute anxiety and feelings of awkwardness or even fear. He therefore experiences **physical sensations** of nervous stomach, heart pounding, sweating and blushing.

To make matters worse these **physical sensations** make John **think** that everyone can see he is very anxious and will consider him to be making a fool of himself as he predicted. This makes his **emotion** of anxiety more intense so that when he does introduce himself his **behaviour** displays nervousness in his speech, inappropriate or incomplete remarks, a rather unfriendly manner and a very abrupt departure.

By introducing the **behaviour** of leaving the situation, John's **emotion** is one of relief and this makes him **think** that he really is incapable of dealing with these social situations and should avoid them in future. This point of view is further supported by the **physical sensations** of exhaustion he feels afterwards which, to him, shows that he's just not up to doing these things because they take too much out of him.

John has identified a category of events about which he has formed some firm beliefs which pre-determine his responses to future events that he associates with this category. He has acquired a pattern which will cause him problems in the future unless he can recognise it and find ways to change it.

The example of John illustrates the back and forth interplays between the internal elements and also the interaction between the internal world of the person and the external environment around him or her.

In Figure 1.1.1 there is a diagrammatic representation of these interactions. In Cognitive Behaviour Therapy we nickname this commonly used diagram the "Hot Cross Bun" and it was originally devised by Padesky and Mooney (1990). We will refer to it often during this book. It illustrates very clearly that despite its name, cognitive behaviour therapy does not focus on cognitions (or thoughts) and behaviour to the exclusion of feelings. However, for the examples above and in the Hot Cross Bun diagram the word "feelings" has not been used: a distinction is drawn between physical sensations and emotions. In daily life people do not always make these distinctions and will use the word "**feelings**" to describe both.

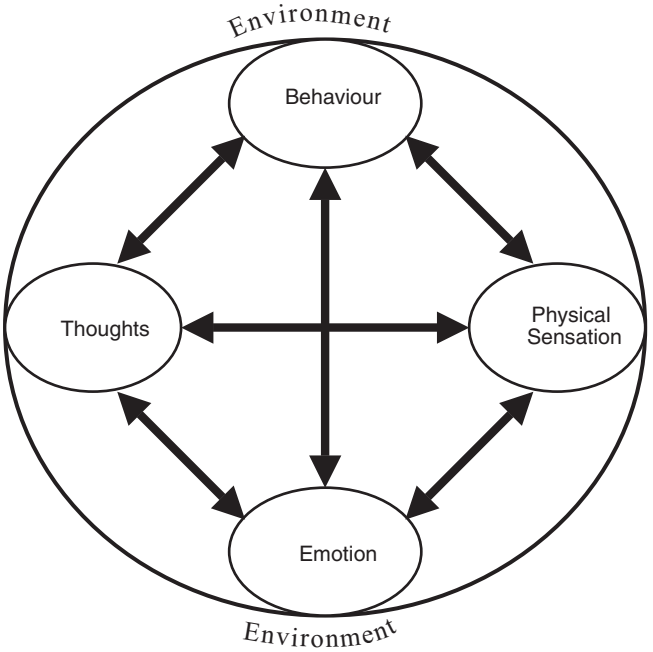

Figure 1.1.1 The Hot Cross Bun (adapted from Padesky and Mooney, 1990)

There are times when in cognitive behaviour therapy it is not important to separate the one from the other, but in work with people experiencing symptoms of physical ill health this distinction is often especially relevant; so explaining, understanding and emphasising this distinction can be very important.

Before leaving this introduction to the concepts of CBT, there are two more that cognitive behaviour therapists frequently use. One of these, like the "hot cross bun", is another image: the "**vicious circle**" (originally referred to as the "exacerbation cycle" by Beck, 1976). This can be illustrated by returning to John for a moment: he had decided that he could not cope with introducing himself to new people; and this caused him to be anxious; in turn his anxiety caused him to fluff his lines; because he fluffed his lines he believed

he was confirmed in his opinion that he could not cope with introducing himself to new people. In this way he completed a "vicious circle" back to his start point.

Self-fulfilling prophesies of this kind are an important feature of what maintains the "distorted thinking and dysfunctional behaviour" referred to by Hawton et al. above. Identifying and breaking these unhelpful circles is an extremely important feature of cognitive behavioural interventions that will be discussed further in this book.

Finally, a quick tour around the cognitive behavioural approach would not be complete without some reference to **automatic thoughts**. Beck (1976) identified these particular thoughts as an important component in recurrent emotional distress. So what are they?

First, recall the example of the hand near the fire. Once I've pulled my hand back from the hot object and decided it is hazardous to me, I do not repeatedly have these thoughts every time I encounter the hot object again. I behave in a way that avoids me hurting myself and I am emotionally wary of being too close to the fire. My reactions seem to be independent of further thinking. Clearly, if I was actually "thoughtless", I would blunder into it and hurt myself; so I have seen it, recognised it as belonging to a certain category (of hot and harmful objects) and then responded according to that judgement. But this thinking process is very quick and I am hardly aware of doing it. We refer to these thoughts as "automatic". They are the immediate interpretive and decision-making thoughts that are triggered when certain events occur in our environment. They are so fleeting and we are so little aware of them that we never think them through. This makes them very powerful and influential because we make decisions based on them and yet, because they are hardly noticed and remain unexamined, they are rarely changed by experience or new knowledge.

A realistic reappraisal of the "hot and harmful, therefore stand back" thought about the fire is unlikely to lead to a change in either my perception of the fire or the decision regarding appropriate behaviour. But John, on the other hand, in our last example, experiences recurrent emotional distress because of his automatic thought that he is "incapable of dealing with these social situations and should avoid them in future". Like the perception of fire, this is also a self-protective strategy that alleviates immediate distress; but it leaves John at a major disadvantage in coping with a category of situations with which he will be faced time after time. Therefore, his episodes of distress will persist until he has had an opportunity to reappraise and change this thought process and the behaviour it directs him towards in favour of a strategy which he finds more effective in both alleviating immediate distress *and* managing the situations satisfactorily.

"Not coping" may often be considered to be the consequence of reducing emotional discomfort at the expense of satisfactorily dealing with situational demands *or* responding to demands at a high personal cost to emotional comfort. "Not coping" experiences are enough of a stimulus to begin an application of the cognitive behavioural model including identification of the automatic thoughts that are at work.

In the next chapter we will examine the relevance of this cognitive behavioural approach to people coping with life-changing physical health illnesses and disabilities, including those who expect their lives to be shortened by terminal illness. However, the cognitive behavioural approach is relevant to the experiences of all of us. We all have situations which we perceive as personal triumphs and disasters; we repeatedly fail to cope effectively with some challenges; we take for granted our abilities and skills that others lack.

Sometimes people very close to us are puzzled as to why we are so unsure of ourselves in circumstances which they consider to be less difficult, and so confident when we face others they consider more difficult. We surprise ourselves at times by taking a strong dislike to something (or someone) for no logical reason.

Recognising the thinking patterns (cognitions), including the automatic thoughts, which underpin these personal behaviours and emotional reactions, can provide all of us with valuable insights into how we cope day-to-day. If that is good enough for our patients then it should be good enough for us. Learning and understanding the cognitive behavioural approach will be greatly enhanced by applying it to oneself. At the end of every chapter there will be exercises you are asked to complete before moving on through this training workbook. Please stick firmly to that way of working unless you are using this book as part of a training course which is covering the same points in different ways.

Whether you are using this book on a course or training yourself, these first exercises in applying the cognitive behavioural approach to oneself are an important place to start the learning process.

Exercises

Before you proceed to the next chapter ensure that you take the time to do the exercises included at the end of this chapter. To use this book properly you need to complete all the recommended exercises.

Exercise 1

1. Think about a good friend who you have not seen in a long time. Remember the good times you have had with this person and the things you like talking to them about.
2. Now, imagine the phone rings; you pick it up; and there is your friend's voice at the other end, calling for a friendly chat. What are your immediate thoughts on hearing their voice? What emotion do you feel? How does your body react? What behaviour do you adopt?
3. Write these things down in the boxes below.

Thought	Emotion	Physical sensations	Behaviour

You may find it easier to fill in some boxes than others. Emotions and physical sensations can be hard to tease apart. Sometimes we do not really notice the thoughts that go with the emotions. The behaviours might be quite small (like a smile or a frown). If you find that one box is still empty, then write in something that is probably the sort of thing that would be the right response. Remember that the responses in the other boxes give you clear clues as to what is likely to be right for this box. For example, if you think "oh dear, what's wrong?" then the emotion is very likely to be worry or anxiety. If the emotion is annoyance then the thought may be something like "this is an inconvenient time to call" or some similar reason to trigger this emotional response.

Exercise 2

1. Imagine you are walking down the street in a local shopping area. It's a pleasant day and you are in no particular hurry, looking in shop windows casually as you walk along.
2. Further on down the street walking towards you but some way off you see a friend who you enjoy talking to and bump into quite often when you are out like this. You smile in this person's direction and feel quite sure that you have been spotted. Suddenly, this person disappears rapidly into the shop nearest to them without acknowledging you.
3. Imagine your reactions to this situation.
4. Now write them in the boxes below.

Thought	Emotion	Physical sensations	Behaviour

You may find you have quite a complicated set of reactions with more than one thought and emotion. Your behaviours may be a mixture too. In completing the boxes, try to ensure you have identified a specific thought for each emotion and vice versa.

Recommended further reading:

Greenberger D. and Padesky C. A. (1995) *Mind Over Mood: A Cognitive Therapy Treatment Manual for Clients,* New York: Guilford Press. A popular workbook for self-help from very influential cognitive behaviour therapists.

Padesky, C. A. and Mooney, K .A. (1990) Clinical tip: Presenting the cognitive model to clients. *International Cognitive Therapy Newsletter, 6,* 13–14 also available at www.padesky.com

Sanders, D. and Wills, F. (2005) *Cognitive Therapy: An Introduction.* London: Sage Publications.

Williams, C. (2003) *Overcoming Anxiety: A Five Areas Approach,* London: Hodder Headline Group. Along with *Overcoming Depression* in this same series, this is a British style of CBT self-help workbook and is backed up with a self-help website at www.livinglifetothefull.com

Chapter 2

The Relevance of a Cognitive Behavioural Approach for People with a Life-changing Illness

Receiving a diagnosis of multiple sclerosis is not an event that will be received unemotionally by Janet, a 33-year-old happily married mother of two. Her reaction to this news is one of intense distress, as it is to her husband and parents. This is not abnormal; it is not the wrong way to react and there is no reason to suppose that because she reacts in this way that she is doing herself lasting harm. In fact, quite the opposite may be true: that to react quietly and calmly with no show of distress could be storing up an emotional dam-burst for later.

At the point of hearing bad news such as this, it is unlikely that CBT has a useful role to play for most people (whether the patient or a close family member). A cognitive behavioural *approach* may, however, have an important role in influencing the thoughts and behaviour of those of us who have to break that bad news or provide professional follow-up since our own thoughts of having "failed" or feeling "hopeless about the future" for this patient may affect our communication and the help we offer.

So, the cognitive behavioural approach is relevant to the way in which health care professionals manage their everyday work with people going through the sorts of adverse life experiences that nobody wants and most people dread.

But just because the distress experienced by patients and their families under these circumstances is "normal" and "understandable", does not mean that there is no place for CBT. People vary greatly in their ability to accept, adapt and cope with the challenges of major health problems, especially life-threatening ones. The methods used in CBT focus on the practical here-and-now experiences in such a way as to be very relevant for those who are struggling to achieve these adjustments.

Early distress may be temporary, but for many people who are faced with life-changing ill health distress will be recurrent: life will become emotionally intense again at every point of change in health status or lifestyle. CBT techniques can be relevant in reducing the emotional intensity of these life events and encouraging a constructive response to new demands. For many people who are challenged in this way and for their families too, elements of CBT may be useful in assisting them to adjust to changed circumstances and also in becoming more resilient to further changes.

So a cognitive behavioural approach can help the health care professional to develop a more constructive attitude and the patient to develop better coping skills. There is, however, a third way in which it can be of relevance and use. The distress experienced by 25–33 per cent of these patients falls within the realms of clinical depression and clinical anxiety. CBT methods have been used to help with these mental health conditions for the past thirty years; they are just as effective when these conditions are reactions to physical health problems.

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Early use of these methods reduces the risk of a downward spiral into a serious mental health problem requiring specialist mental health expertise.

In examining the relevance of a cognitive behavioural approach to people with life-changing ill health and their families, it is necessary to say something about what it is not. It is *not* "positive thinking". It does not involve trying to put a shiny gloss on things; stating positive affirmations in front of the mirror; pretending that things are better than they are; emphasising the good things and ignoring the bad; reassuring oneself that everything will get better; or deluding oneself into believing that this is an opportunity not a threat. These mental tricks may have their place in motivating a sales team, but they usually prove unsustainable in circumstances of intense emotional experiences and they do nothing to equip people for coping well with setbacks.

Returning to our theme of applying CBT to people with life-changing illness, let us look at how we might apply the Hot Cross Bun model to William's experience of a diagnosis of cancer. Figure 1.2.1 recaps the Hot Cross Bun in a way that will fit our example.

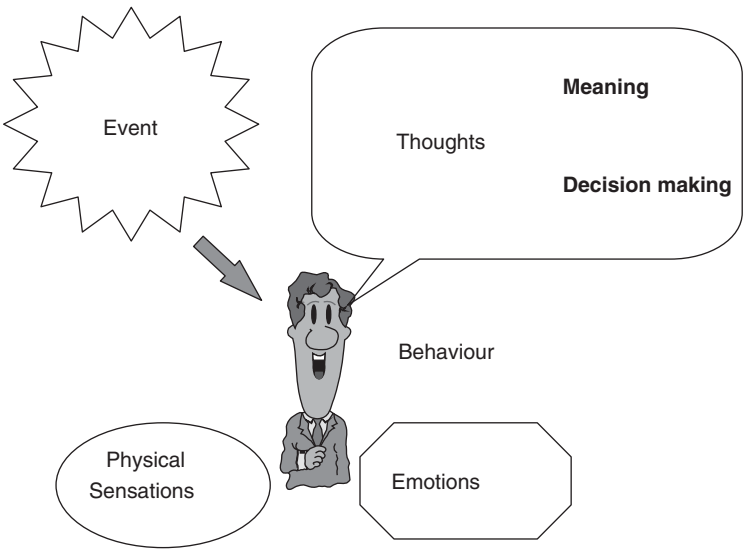

Figure 1.2.1 The cognitive behavioural model

Figure 1.2.2 illustrates a set of responses to this diagnosis of cancer. In this response set, the patient's **thoughts** express immediate defeat and self devaluation. Such strongly held beliefs will understandably lead him (we will call him William) to decide on **behaviours** that are passive and retiring, which (because he is doing nothing) will increase the **emotion** of hopelessness whilst his loss of drive leaves him with a **physical sensation** of being very tired all the time. Each of these four elements will feed back into each other and help to maintain or even escalate this depressive response set. We will refer to this as Response Set 1.

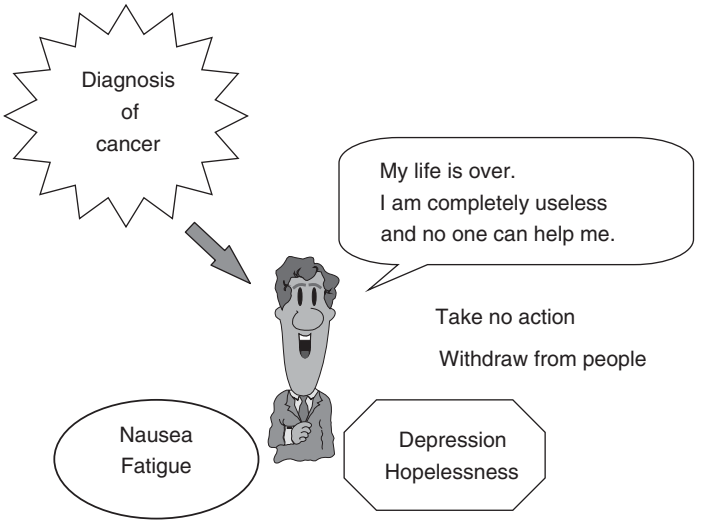

Figure 1.2.2 Response Set 1

An alternative response set is illustrated in Figure 1.2.3. This patient (William 2), facing an identical challenge, has a different (but *not* a "positive") perspective and the effects are different. The **thoughts** are acknowledging a difficult future, as in Response Set 1, but this time in a constructive way. These thoughts help him decide on **behaviours** which are intended to be useful in dealing with his situation. The **emotions** remain negative in nature but not overwhelming, instead adding some driving force which affects his **physical sensations**, making him feel energetic (perhaps even restless and tense). The restless energy will probably help him overcome reticence in telling people and getting on with his planning. As the plans develop, so he is able to focus on constructive things that he is doing, which in turn reduces sadness and encourages further helpful ideas.

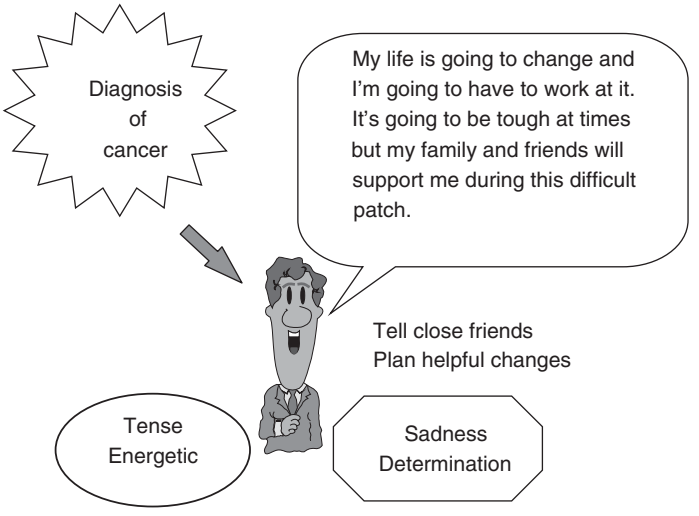

Figure 1.2.3 Response Set 2