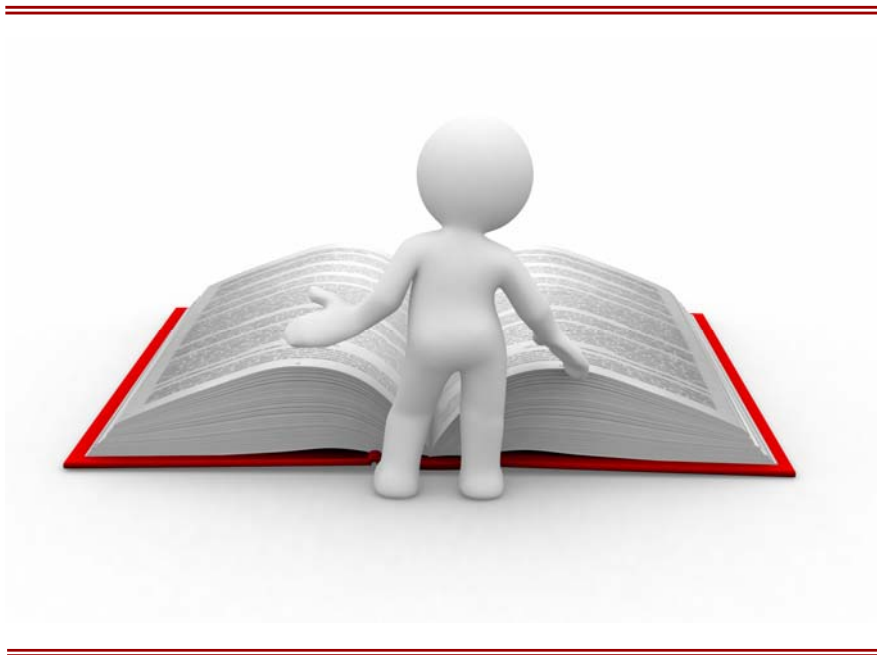




# CHRONIC PAIN, LOSS AND THE FUTURE





*This booklet has been developed through collaborations between “Keeping Pace With Pain”, a chronic pain support group, and Dr Sally Curtis from the Faculty of Medicine, University of Southampton.*

*The idea for this booklet arose with the aim of informing and helping others with chronic pain.*

*We appreciate that reading and thinking about the losses we experience may be upsetting. If you find that this has affected you please either make an appointment to see your GP or refer to the useful web links and telephone numbers provided on the back cover of this booklet.*

*We hope that you will find this booklet useful.*



## **Foreword**

**by Jessica** *(A Member of Keeping Pace With Pain)*

**I have been living with chronic pain for nearly 9 years. It wasn't until recently that I associated the stages of loss with the different thoughts and feelings I have gone through with chronic pain. Living with constant pain is a roller coaster ride with lots of highs and lows along the way which, I'm sure if you are reading this, you may identify with. When I was first told there was nothing that could be done to help me and that I would have to live with pain it felt like suddenly everything had changed. I became depressed, lost hope and grieved for the life I had once had. I wish someone had been there at the time to tell me that it was ok, feeling like this was normal, not something to feel silly or ashamed about. It's normal in our situation to go through these feelings, they are all part of the process of learning, accepting and realising a new identity. At some point the way I was feeling changed, I didn't feel so lost and down I had begun to begin to accept and learn to live with chronic pain. I was gaining a new identity. I wasn't the same as I was before I had pain but I was still me, just me with pain. I was learning to accept my limitations and to live with them. I still have constant pain, I still get days when I am angry and frustrated but on the whole I feel able to cope with it all much better now. Ok, so it's not the way I had imagined my life would be but I think I have finally accepted that you can live with chronic pain.**



## Introduction

The realisation that pain has become chronic or persistent can have profound effects on an individual and quality of life. Frequently, it is not simply the pain that you have to learn to manage or cope with, it is also the many



other life changes that can accompany it. Such changes can include those affecting work and consequent financial hardship, leisure and hobbies as well as relationships and self identity.

Theories of loss are traditionally associated with grief, these relate to the individual, their families and friends and also to society. However, as you will see when you read this booklet, the theories can also relate to the changes individuals can experience when living with chronic pain.

The main aims of this booklet are to help you to:

- ◆ Live with chronic pain
- ◆ Appreciate the impact of loss associated with chronic pain
- ◆ Gain a new and positive perspective on your pain experience
- ◆ Reorganise your achievements
- ◆ See that life with chronic pain can still be fulfilling and satisfying



## Theories of Loss

In 1969 Elisabeth Kübler-Ross M.D.<sup>1</sup> a Swiss-born psychiatrist, identified five stages of loss for individuals who were suffering a serious illness. These stages were: **Denial**, where an individual believes there is a mistake in the information, relating to their condition, they have been given. **Anger**, where an individual may ask the question “Why me?” and possibly display hostility while trying to regain some control of their life. **Bargaining** may occur when a person tries to identify their problem and attempt to regain their previous lifestyle. **Depression** may result from the realisation that the situation is permanent. Finally, **Acceptance** of the situation and the effect it will have on their life.

“The one thing that usually persists through all these stages is hope.... ”  
- *Elisabeth Kübler-Ross*

In 1971 Colin Murray-Parkes<sup>2</sup>, a British psychiatrist, proposed six stages of loss for individuals who had lost a close friend or relative, the stages he described were: **Alarm**, which occurs when the loss is first realised. This is often accompanied by high levels of stress. **Searching**, this often manifests as seeking out what is lost or being unable to let go of what has been lost. **Mitigation**, in grief this is often represented by an individual believing their loved one is nearby, in chronic pain this could be interpreted as feeling the cure is just around the corner.



**Anger and Guilt** often go hand in hand. Anger and resentment can be expressed as a result of the loss, which can be directed at yourself or at those around you. Guilt can be shown in response to the displays of anger, but also at the restrictions that the loss imposes and how that impacts on those around them.

**Gaining a new identity** in grief can occur when people take on the characteristics of those they have lost, in people with chronic pain it can be the realisation that the way you live your life has changed and not to resist this. Colin Murray-Parkes also identified **unresolved grief**, where an individual is unable to accept the loss. This could result in becoming “stuck in a stage” and unable to resolve the loss in context of their lives. This work is based upon a person’s recovery from loss and looking positively to the future.

Identifying how aspects of an individual’s identity can be altered or lost can help to address potential resistance and anxiety to change. This can help with the acceptance of a new or altered sense of self



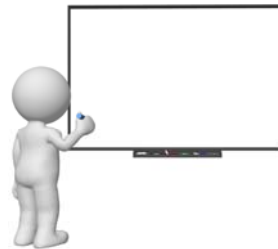
John Bowlby<sup>3</sup>, a British psychologist, psychiatrist and psychoanalyst, developed a model to describe the effect of bereavement in adults to loss and attachment. He too used stages to describe common responses to loss.



**Numbing** is an immediate response to loss and feelings of anxiety and anger are often present. **Yearning and searching** this can present as feelings of pining and distress. There is also restlessness and a preoccupation with thoughts of the loss. Anger is common and sometimes intense. **Disorganisation** can occur where feelings of searching and despair along with anger are compounded by the inability to perform tasks or continue with the lifestyle that was present before the loss.

This realisation can often lead to despair and depression.

**Reorganisation** occurs when an individual begins to come to terms with the new situation and starts working towards accommodating it. This can be where an individual uncovers a new or altered self identity.



There is no right or wrong way of experiencing loss, and likewise there is no right or wrong way of moving through the different stages. What you experience and the order in which you progress through the stages is a very individual and personal experience. The dual process theory proposed in 1999 by two professors of psychology from the Netherlands, Margaret Stroebe and Henk Schut<sup>4</sup>, states that individuals do not normally go through the stages in an orderly or organised fashion.

You may go through more than one stage at once, not experience a stage at all, or bounce backwards and forwards between different stages over time.



You have to remember that what you go through is right for you; each journey is a unique one. Along with feelings of loss the basic assumptions we make regarding our lives and the future can change. This can cause a person to ask themselves many questions, for example who they were, who they are now and how their perceived future has changed.

In 2001 the psychologist Robert A. Neimeyer PhD<sup>5</sup>, developed the Meaning Reconstruction Theory in order to try and make sense of the changes that occur with loss and how they impact on the future. Meaning Reconstruction places an importance on a person's need to determine a new sense of purpose.

It is hard to try and regain control in response to such life changing events. One way to try and take control back is to start by altering the way you live your life and changing your thought processes. It is hard to change the way that you think and live when suddenly everything in life changes, like a rug has been pulled out from under you. However allowing yourself time to move through the different stages and acknowledging your feelings will in time hopefully allow you to look into the future in a more positive way.







## **Map Your Own Pain Experience**



Mapping your experience using the theories of loss, from the first realisation of having chronic pain followed by the effects of living with the pain, may provide a new perspective on your life.

On the following page you will find some words that can be used to describe the impact of living with and adjusting to loss. By writing down and linking words together that are relevant to you and your life, you can map your own experience of living with chronic pain.

Reflecting on your own personal experience may allow you to see how far you have come and how much you have achieved. This is frequently overlooked in our everyday lives. It can bring a new insight and, with it, positivity and hope.

**Examples of mapping exercises completed by individuals with chronic pain can be found on pages 11, 12 and 13.**

*There are **two sets of stickers** included in the back of the booklet for you to use to map your own experience of living with chronic pain. You can use one set now and the other set in the future to enable you to reflect upon changes that could occur.*



## **Map Your Own Pain Experience**

Words that can be used to describe the impact of living with and adjusting to loss.

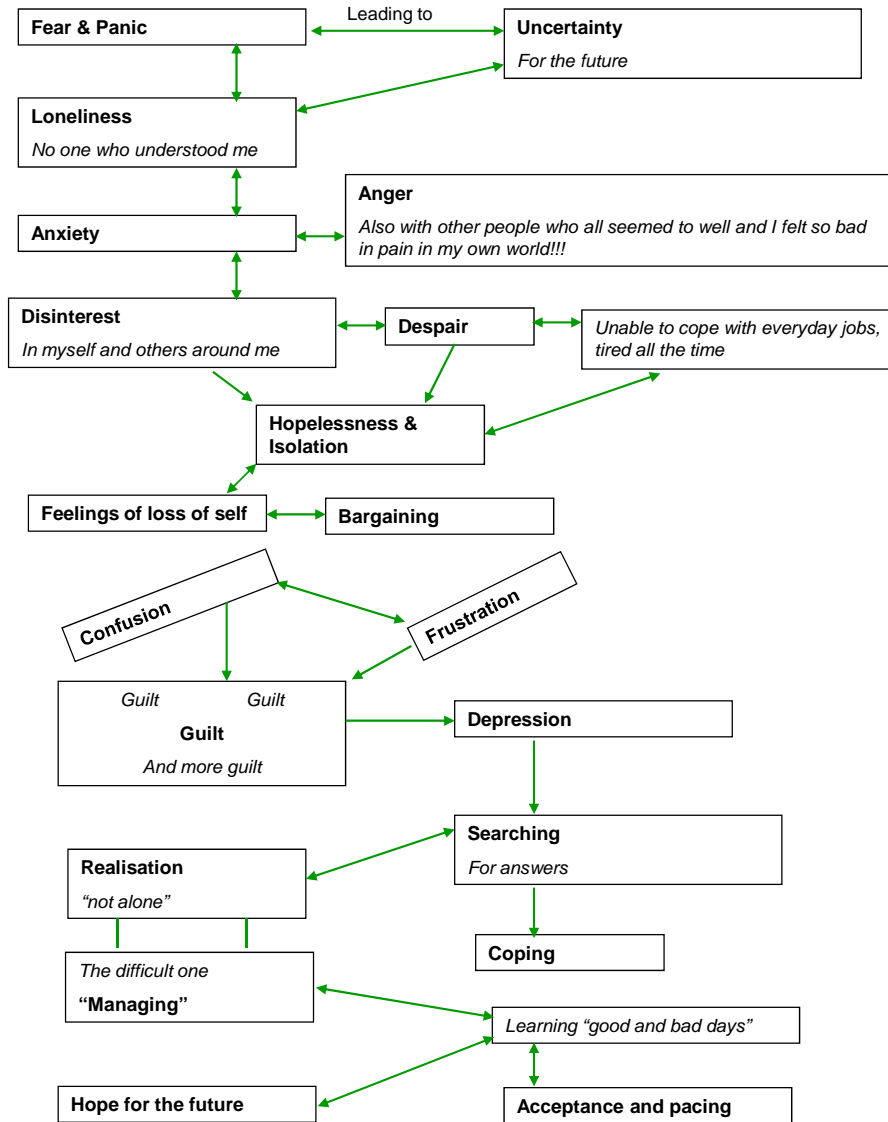
**Positivity**                      **Denial**                      **Alarm**                      **Anger**  
**Bargaining**                      **Hopelessness**                      **Guilt**                      **Hope**  
**Gaining a new identity**                      **Despair**                      **Numbness**  
**Shock**                      **Frustration**                      **Fear**                      **Disorganisation**  
**Feelings of loss of self**                      **Coping**  
**Managing**                      **Acceptance**                      **Realisation**  
**Uncertainty**                      **Yearning**                      **Motivation**                      **Thriving**  
**Disbelief**                      **Depression**                      **Confusion**                      **Searching**  
**Disinterest**                      **Anxiety**

This list is neither exclusive nor exhaustive. You can use as few or as many words as you like and add other words that you feel apply to you. You can add descriptions or arrows to indicate detail and direction.

**You may find it easier to undertake this on a day when you are feeling more positive.**

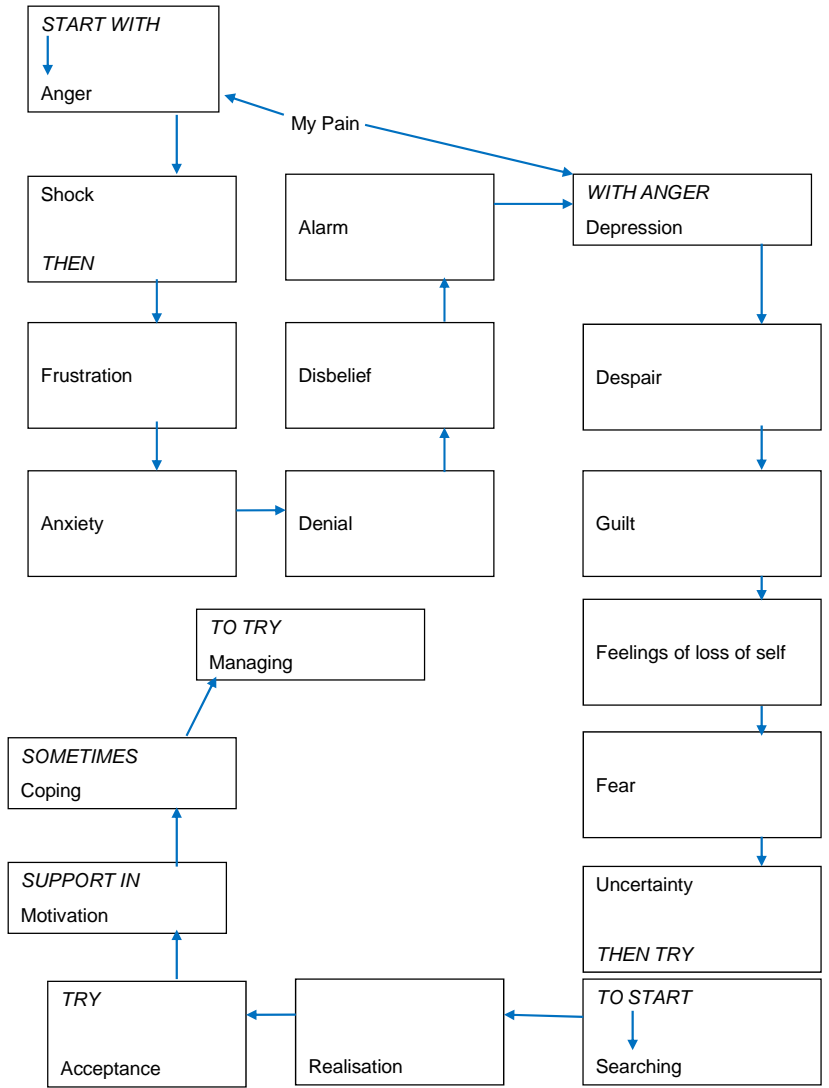


## Real Life Experiences



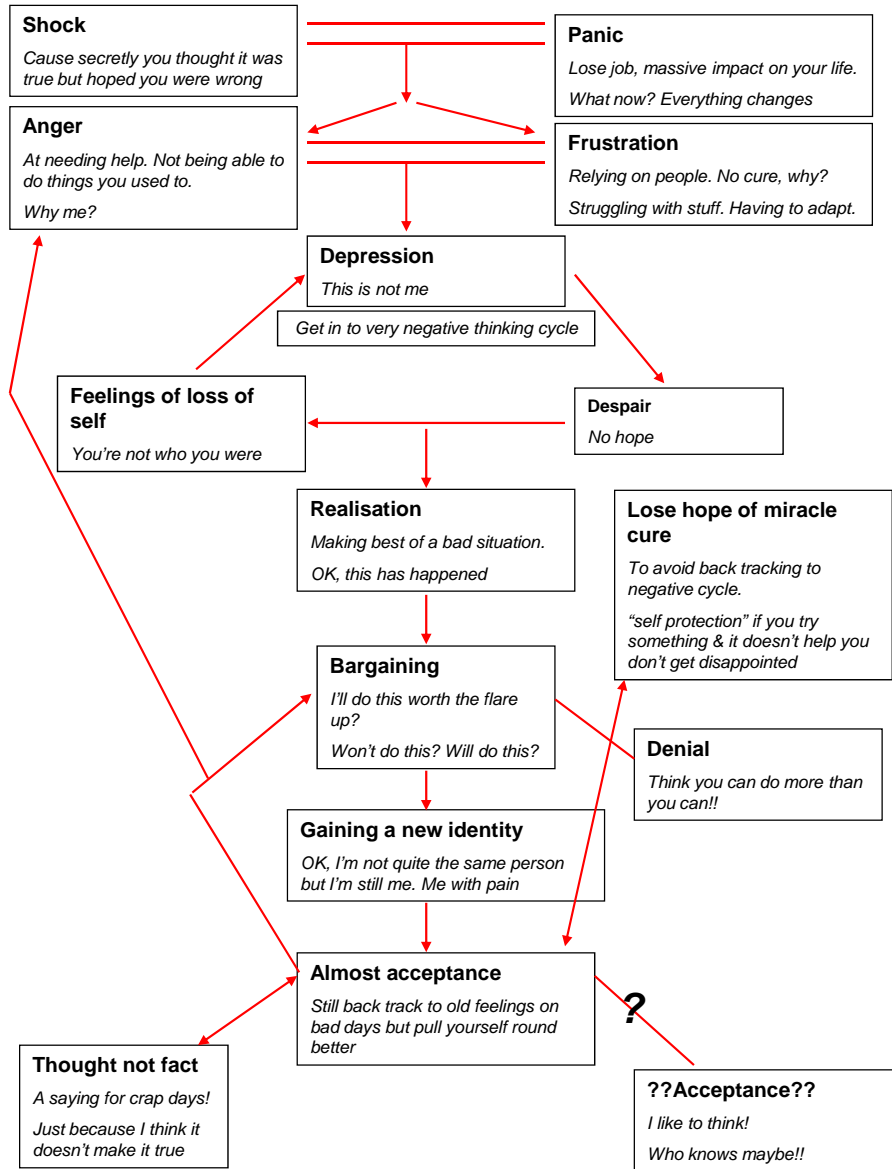


### My pain journey





Get told “this is it, there’s no more we can do for you” chronic pain “cycle” begins...





## Support

Working through your pain experience may not be an easy thing to do. It may remind you of difficult times and emotions you have encountered.

However, the purpose of this booklet is to help you to look forward to the future with hope and positivity. Relating the stages of loss to living with chronic pain may help you with the recognition of a new or altered sense of yourself and reduce possible feelings of isolation.

It may provide you with the opportunity to gain a new, possibly more objective, perspective on your pain experience.

You may also be able to see how far you have come since developing chronic pain, and the positive changes you have made, which are not always apparent in day to day living. It is important to be good to yourself and to reward yourself for all the things that you achieve in life.





Taking up a hobby can be great for providing a new focus. We have included a few of the things that we have found helpful when coping with our pain.

- ◆ Painting and arts and crafts, photography, reading or listening to audio books, listening to music or learning to play a musical instrument. These types of activities can be a welcome distraction from the pain.
- ◆ Volunteering for a local or national charitable organisation. To be able to help others for few hours here and there, wherever possible, can be very rewarding.
- ◆ Joining a support group can reduce the feeling of being alone with pain, talking to others and sharing experiences can be beneficial and reduce feelings of isolation.





The thoughts and reflections of individuals who related their pain to the theories associated with loss, by undertaking the exercise, are presented below.

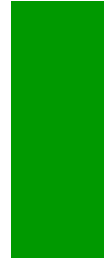


“Since the age of 14 I have suffered pain in both knees which over the years has resulted in operations and constant pain.

In the last 5 years I have attended the pain clinic and been informed that I suffer with neuropathic pain, I have tried to understand and accept why I have this pain, until I completed the exercise.

When starting the exercise I realised the pain path led to anger which made me realise that I could have handled myself better instead of giving loved ones a hard time. I should have communicated better instead of holding in especially when the depression set in, I felt that if I had completed the exercise sooner I might have handled the way I reacted to people in a different way and also sought help sooner. I feel by doing the exercise it would help you come to terms with what you are going through and possibly help you see the way your body and mind are coping with pain”.





“I found this exercise physically easier to do than I expected. It gave me a space limit to the project; I have a tendency to waffle so I was determined to limit myself to one side of A4 paper. After 4 years of first having attended the pain clinic, it was very useful to review my progress. Sometimes I feel that I’ll never accept my situation, but this exercise has helped me see that I have actually moved forward. The single words I used helped to focus my mind.

I find it very interesting and reassuring that grieving/bereavement are gradually being accepted as applying to issues other than death. The pathway to acceptance of a situation is different for everyone and, yet again, it is important particularly for medical staff to understand the link between mind and body”.

“My experience of completing the exercise was like a journey for me, it made me think back to the beginning and the emotions I went through and how there was "some sort" of light as the journey continues onwards. The completion of the exercise makes one realise that there is still a life to be lived but it was different from how I imagined it to be and it was not so awful as I thought”.





**This booklet was written by people with chronic pain to explore feelings of loss and how it affects quality of life.**

**We sincerely hope that it will help others with this condition to live more enriched lives and never give up hope.**



**References:**

<sup>1</sup>Kübler-Ross, E. (1973) *On Death and Dying*, Tavistock/Routledge

<sup>2</sup>Murray- Parkes, C. (1996) *Bereavement: studies of grief in adult life*. 3<sup>rd</sup> edition Routledge

<sup>3</sup>Bowlby J. (1980) *Loss: Sadness And Depression (Attachment and Loss)*. Basic Books

<sup>4</sup>Stroebe, M, and Schut H. (1999) *The Dual Process Model of Coping with Bereavement: Rationale and Description.* *Death Studies* 23:197–224

<sup>5</sup>Neimeyer RA. (2001) *The Language of Loss*. In *Meaning Reconstruction and the Experience of Loss*, RA Neimeyer (ed). Washington, DC: American Psychological Association



# CHRONIC PAIN LOSS AND THE FUTURE

## USEFUL WEB LINKS & TELEPHONE NUMBERS

[www.keepingpace.co.uk](http://www.keepingpace.co.uk)

023 8046 5019

[www.britishpainsociety.org](http://www.britishpainsociety.org)

020 7269 7840

[www.backcare.org.uk](http://www.backcare.org.uk)

0208 977 5474

[www.fibromyalgia-associationuk.org](http://www.fibromyalgia-associationuk.org)

0844 887 2444

[www.samaritans.org](http://www.samaritans.org)

08457 90 90 90

[www.cancerhelp.org.uk](http://www.cancerhelp.org.uk)

0808 800 4040

[www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

020 7380 6500

[www.macmillan.org.uk](http://www.macmillan.org.uk)

0808 808 00 00

[www.painconcern.org.uk](http://www.painconcern.org.uk)

0131 669 5951

[www.crusebereavementcare.org.uk](http://www.crusebereavementcare.org.uk)

0844 477 9400

[www.depressionalliance.org](http://www.depressionalliance.org)

0845 123 23 20

[www.paincommunitycentre.org](http://www.paincommunitycentre.org)



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Printing funded by NAPP Pharmaceuticals Limited