The struggle to maintain joy and a fulfilling relationship while coping with chronic pain and illness is a serious problem for millions of people today.

On average, one in five adults suffer from chronic pain. In older people, the number rises to three in five. Most of these people don't realize they don't have to settle for a survival-based coexistence with their partner or bury their hopes for success and joy under a mountain of heat packs.

Drawing on the latest research as well as her personal experience with how to live a joy-filled life in spite of suffering, author Karra Eloff has developed a low-energy, highly practical path to a remarkable new normal for anyone living with pain. She sets out simply and clearly how you can move the dial of a relationship challenged by chronic pain from embattled and exhausted to joyful and passion-filled. It's possible through small, practical changes that require little energy but make a big impact in the areas of:

- » communication
- » mental health
- » intimacy, and
- » personal success.

If you experience chronic pain or love someone with a chronic illness, this book is for you. And if you are a health professional seeking practical advice for people with persistent pain, this book is for you too.





UK £19.99 US \$27.99 CAN \$37.99

HEALTH & WELLBEING

he hronic Pain Couple Karra Elof

'Reading Karra's book feels like talking to your best friend — who gets it, has the best advice, and tells it to you straight!'

– Sally Shepherd, Clinical Psychologist and Author

The Chronic Dain Couple

> How to be a joyful partner & have a remarkable relationship in spite of chronic pain

# Karra Eloff

# The Chronic Pain Couple



Karra Eloff is a health professional, speaker and entrepreneur dedicated to helping suffering people find joy. She is the managing director of two private psychology clinics on the east coast of Australia, and is also the founder of The Chronic Pain Couple, an organization that delivers practical support to people with chronic pain

and their loved ones. Karra is a wife, mother and former speech pathologist who featured as a regular guest panellist on the TV talk show *Be That*.

# The Chronic Pain Couple

How to be a joyful partner & have a remarkable relationship in spite of chronic pain

# Karra Eloff



### First published 2022

Exisle Publishing Pty Ltd PO Box 864, Chatswood, NSW 2057, Australia 226 High Street, Dunedin, 9016, New Zealand www.exislepublishing.com

Copyright © 2022 in text: Karra Eloff

Karra Eloff asserts the moral right to be identified as the author of this work.

All rights reserved. Except for short extracts for the purpose of review, no part of this book may be reproduced, stored in a retrieval system or transmitted in any form or by any means, whether electronic, mechanical, photocopying, recording or otherwise, without prior written permission from the publisher.

A CiP record for this book is available from the National Library of Australia.

ISBN 978-1-922539-21-2

Designed by Enni Tuomisalo Typeset in PT Serif, 11pt Printed in China

This book uses paper sourced under ISO 14001 guidelines from well-managed forests and other controlled sources.

 $10\ 9\ 8\ 7\ 6\ 5\ 4\ 3\ 2\ 1$ 

### Disclaimer

This book is a general guide only and should never be a substitute for the skill, knowledge and experience of a qualified medical professional dealing with the facts, circumstances and symptoms of a particular case. The nutritional, medical and health information presented in this book is based on the research, training and professional experience of the author, and is true and complete to the best of their knowledge. However, this book is intended only as an informative guide; it is not intended to replace or countermand the advice given by the reader's personal physician. Because each person and situation is unique, the author and the publisher urge the reader to check with a qualified healthcare professional before using any procedure where there is a question as to its appropriateness. The author, publisher and their distributors are not responsible for any adverse effects or consequences resulting from the use of the information in this book. It is the responsibility of the reader to consult a physician or other qualified healthcare professional regarding their personal care. The intent of the information provided is to be helpful; however, there is no guarantee of results associated with the information provided.

To my husband Johann,

Thank you for believing with me that remarkable was still possible.

## CONTENTS

### PART 1: THE PAIN

1. A remarkable relationship	11
2. On pain	21
3. My story	33
4. Communication hack #1: Communicating need	41
5. Communication hack #2: Communicating love	57
6. Communication hack #3: Fighting fast	67

### PART 2: THE HIDDEN PAIN

7. Kissing cousins: Pain and mental health	
8. Trauma and chronic pain	
9. The power of negative thoughts	101
10. Uncovering your core beliefs	111

### PART 3: MENTAL MEDICINE

11. Self-compassion	123
12. A different perspective	135
13. The other side	151
14. Supporting your partner	159

### PART 4: ON SEX

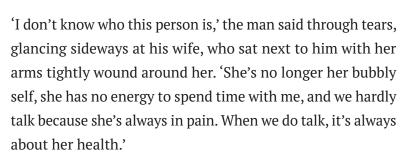
15. Sex matters	175
16. The problem of desire	183
17. When sex is painful	197
18. Making changes together	

### PART 5: THE NEW NORMAL

19. The journey towards a new normal	219
20. Pivot and reach	229
Your beginning	239

Acknowledgments	243
Endnotes	245
Index	258

## INTRODUCTION



His wife blinked but showed no other reaction.

The woman opposite him then spoke softly. 'I can't do our usual outings with my husband any more. A simple thing like going to a restaurant has become difficult.'

Another man chimed in. 'I've quit my job to take care of my wife. She's emotional all the time.' He paused before adding, 'Our relationship was over the moment she became sick.'

INTRODUCTION

These are some of the comments I heard the first evening of a pain support group for couples I co-facilitated. Everyone appeared grief-stricken and exhausted. No couple was sitting close to one another or being affectionate. Not one hand was held.

The struggle to maintain a passionate and fulfilling relationship while coping with chronic illness and pain is a serious problem for millions of couples today. On average, one in five adults suffers from chronic pain. For those older and hopefully wiser individuals, the number rises to three in five.<sup>1</sup>

Chronic pain is defined as any persistent or intermittent pain that lasts more than three months. No doubt you already know this, though. Like me, maybe you found yourself going online in a desperate search for someone — anyone — to tell you how to keep pain from stealing your joyful marriage. Except for a few articles advising how to 'survive pain and sustain a relationship' there's not much out there that speaks to this problem. Besides, I don't think anyone wants to just *survive*. I also don't believe any couple wants a relationship that's just *sustained* either. Do you? No, I didn't think so, which is the reason for the book you're holding in your hand. I know what chronic pain and illness can do to a relationship. My life was once focused on the daily burden of managing persistent pain while I watched, in alarm, as the romantic connection with my husband slipped away. Often, we planned dates as if I was well, ignoring the fact that I could barely make it out the door, let alone be good company. Across from each other in a beautifully dim-lit restaurant, our main topic of discussion was how long I could tolerate sitting before the pain became too uncomfortable and we needed to leave. So much for enjoying a romantic evening!

Thankfully, this struggle was short-lived. Not because my pain decreased or went away, but because we made a decision *together* not to allow the illness and pain that had entered my body to sidetrack our relationship. I dug deep into the available research and by applying practical strategies from my findings, as well as some select clinical strategies we have taught hundreds of our clients and continue to use ourselves on a daily basis, I identified the key steps that returned joy to our love life despite chronic pain.

I should explain that I'm a speech pathologist, now managing director of two private psychology clinics, and my husband Johann is a clinical psychologist. Every week, our team of

2

psychologists welcomes hundreds of people into our clinics who are facing serious, life-altering crises, including chronic pain issues and relationship distress. Not surprisingly, many chronic pain couples find themselves on the verge of divorce and unable to find the practical support they desperately need. Like you, their focus on daily survival has rendered their ability to have a flourishing, fulfilling *and* passionate relationship out of reach. *Or so they believe*.

Over time, brave couples can learn to break the stronghold that chronic pain has had on their relationship — and once again feel the glow of intimacy, both emotional and physical, in spite of their daily battle with pain. Such a transformation requires a multidimensional approach, changing specific aspects of your mindset, lifestyle and ways of relating.

Now, if you happen to be reading this from under a mountain of duvets or heat packs, you might doubt you have the energy to tackle all that change. I understand if your response is something like, 'Look, having a great relationship sounds good, but I'm so exhausted I can hardly deal with the demands of my daily routine, much less handle a bunch of new complicated strategies.'

But I'll let you in on a little secret.

When couples turn towards each other and refuse to let their circumstances of chronic illness and pain control their love and their lives, the relationship experiences a powerful strengthening. That's when the journey to a new normal begins. Even when you're fatigued (read: need more rest than an entire retirement village), it *is* within your power to have a great relationship — in fact, a remarkable one. The key is making small practical changes that require little energy but make a big impact.

INTRODUCTION

You don't have to settle for a passionless relationship or a dull, survival-based coexistence with your partner. You're worthy of love, and no matter your condition and level of pain, you're capable of a fulfilling and passionate relationship.

### Five steps: The path to joy

In the development of effective strategies, I lay out five areas that pave a new path to joy for couples up against the daily struggle with chronic pain. This roadmap to a remarkable new normal will lead you and your partner to a new, deeply satisfying life.

Here's some of what you're going to learn and experience in the pages that follow, that will support you in creating an

INTRODUCTION

ongoing, loving relationship. (Remember: small changes = big impact.)

- 1. The importance of being on the same team as your partner.
- Practical tips for communicating about your condition, to make space for more romance and fun in your relationship.
- 3. How to develop self-compassion and master your emotional wellbeing so that you can become a more joyful partner.
- 4. How your pain and brain relate to each other and how it affects your relationship.
- 5. How to enhance your sex life despite pain.

Note that this book has been written as if I am talking to the person who is experiencing pain, so if you're a health professional or a partner supporting a loved one in pain (how wonderful you're investing in your relationship in this way), please know that this book is as much for you as it is for your partner. Please don't be distracted by my direct address of the reader. Besides practical strategies, you'll also find information about the current research on pain, relationships and mental health, which may give you a new perspective on your experience. Keep in mind, however, that it isn't intended to be a substitute for professional medical advice from your GP and healthcare team.

### Take it slow and easy

Finally, for those of you who suffer from chronic pain and seek to re-establish a loving connection with your partner, be gentle with yourself while you work through the chapters. Allow time to slowly digest the information, perhaps a couple of pages at a time. Expect your concentration to be short and your energy low, and know that not every strategy in this book will relate to your situation. Still, I invite you to be open to change in all areas of your life, not just in your relationship. The more you understand and love yourself, the easier it will be for your partner to understand and love you, too.

# PART 1 THE PAIN

# 7)

All things remarkable are surprisingly simple; albeit difficult to find. –Criss Jami

# **1** A REMARKABLE RELATIONSHIP

While out shopping one morning, I was stopped abruptly by a hand pulling at my arm and spinning me around to face a friend I hadn't seen in a month. Although usually bright and bubbly with a smile, she was visibly worn out and appeared grief-stricken.

'Karra, Rob's back operation didn't go as planned. He's still in a lot of pain, and it's been four months.' She leaned in closer as if she were sharing a secret. 'I don't know how much longer I can be strong for him. I love him, but I'm so tired. I need to do everything around the house, and he's not the same man he was before the back injury. It's so hard. You know what I mean, right? Isn't this the kind of problem you help couples solve?'

She let go of my arm, but her sense of desperation still gripped me.

## The big question

Is it really possible to break the stronghold pain has on your relationship? That's the big question she was actually asking, and I often hear similar questions from couples, some of whom are teetering on the edge of giving up.

I can relate. Before pain entered my body, Johann and I used to enjoy exercising together each evening, followed by unwinding on the couch as we shared the triumphs and challenges of our day. As the months and years went by without my health issues resolving, my battle with pain became the usurper in our relationship. We'd sit at night side by side, silenced by exhaustion. The fatigue was at a level I'd never known before, and my husband was drained from caring for me more than he cared for himself. We had nothing left to give each other, only a vague hope that I might get better so that we could get back to 'normal'. By the time couples realize they need help finding a new normal, many are so overwhelmed and drained by the daily battle of pain that they (understandably) doubt their ability to restore their lost intimacy and spark. With what energy? And where to start? By all accounts, pain has robbed them of their ability to support and comfort each other.

Research confirms that chronic illness and pain are a huge challenge for couples to navigate.<sup>1</sup> A partner experiencing chronic pain can be a cause of decline in relationship satisfaction, an increase in home-life stressors, and can put both partners at risk of developing mental health problems.

So, I want to ask you an important question: How has pain impacted your relationship?

In my own research, I've encountered two primary types of chronic pain couples. The first couple I come across has lost the spark in their relationship, making it harder to connect as in the past. However, they are a well-connected couple, which means they've still managed to stay close to each other. What they're looking for is a fast track to a 'new normal' so that they can live joyfully together, as if the pain isn't there. The second type of couple is the one for whom the pain has really changed the partner and/or relationship. This couple is completely depleted, not able to draw closer to each other, and left wondering how or if they can stay together. The partner not in pain often pushes their 'needy' partner away, and the partner in pain feels they aren't getting the support they need. Whether you see yourself in the first or second description, this book is for you.

### What is 'remarkable'?

Despite this dark picture, the answer to the big question is yes, it's possible to forge a path to remarkable — to move the dial of your relationship from embattled and exhausted to joyful and fulfilling. I assure you that this is no unrealistic fantasy.

Consider the meaning of *remarkable*: 'worthy of attention; striking'. I chose this word to define the goal for your relationship because, in my experience, when a couple is bursting with appreciation, love and joy, they stand out. Their connection is striking to those around them, and their love for each other draws attention. You can't hide remarkable love. It seeps into everything you do (a lot like chronic pain if you allow it). A relationship is a space where your identity and sense of security are shaped. This space provides us with meaningful roles and purpose, and when we as individuals are built up in the arms of the one we love, our confidence and wellbeing are striking. What you can achieve because your loved one believes in you is striking. What you can give to others because you're being given so much in your relationship is worthy of attention, and what you can rise above because your partner stands with you is remarkable.

Of course, remarkable doesn't just happen, especially not when you're suffering from chronic pain. It requires a choice activated by love and translated into practical strategies that allow you to rise above challenging circumstances. Remarkable requires you and your partner to make a special effort — no, a commitment — to refuse to allow suffering to threaten your most intimate connection. It doesn't mean that emotions of frustration, anger, or disappointment won't arise. But they won't dominate or interfere with the extraordinary love you're capable of giving and receiving.

You may have noticed that I haven't described what a remarkable relationship looks like by listing signs or actions as evidence. There are two reasons. First, because

14

a remarkable relationship is specific. It's unique to you and your partner's personal life experiences prior to this moment.

Second, explaining the outward manifestations of my remarkable relationship and foolishly encouraging you to set such markers as *your* aim will not be effective. Remarkable relationships are built from the inside out. I can assure you, however, that following the guidelines presented here in these pages can take you there.

When your relationship takes a turn toward remarkable, your physical and psychological health will improve<sup>2,3</sup> and you might find you can't keep yourself from kissing your partner, listening to them or dancing with them. The outpouring of love you can experience when you follow the practical steps in this book will be as unique as your pain profile.

### The journey begins

One morning, while in the shower getting ready for work, I passed out.

I suffer from spondyloarthritis, a type of arthritis that, for me, inflames the spine and sacroiliac joints (where your lower spine and pelvis connect), as well as peripheral joints. Just to make it more fun, it also results in enthesitis (inflammation where ligaments and tendons attach to bone) and it has affected various organs. According to my specialists, I'm a 'treatment-resistant' individual. This means the medications that work for the majority of people with the same condition don't work for me.

After I passed out in the shower, the next thing I remember clearly was Johann at the foot of the hospital bed speaking with the doctor.

'Can you tell me about her most painful joint?' the doctor asked Johann.

'It's her hip,' he replied, pointing in the general direction of his right hip.

I was surprised Johann wasn't able to name the sacroiliac joint we had spent thousands of dollars treating.

'What medications does she take?' the doctor continued.

Johann said something inaudible then came to the side of my bed and searched my handbag.

As I lay watching that interaction, I recognized the small pieces of information about my condition and treatments

that Johann was unable to explain. Not because he lacked concern. I just hadn't educated him during those first months on the finer details of my health journey. I remember feeling as though I'd invited him to join me on a sports field to play a game he could name, but he didn't know the rules.

### Are you on the same team?

Getting on the same team is the first all-important step on the journey to remarkable. In the book *The Seven Principles for Making Marriage Work*, world-renowned marriage researcher Dr John Gottman and co-author Nan Silver explain the importance of knowing your partner's 'love map', an understanding of each other's world.<sup>4</sup> As author Steve Maraboli points out, it's the two of you versus the illness, rather than one partner against the other.<sup>5</sup>

To draw closer to your partner and experience a remarkable relationship, both of you need to share a strong foundation of understanding your condition. It begins with expanding your love map to include the details of your pain. You need to be on the same page about your pain and the ways your health currently challenges you, both personally and as a couple. It's you and your partner versus chronic pain. Not you and pain versus your partner. When you believe this, you're already a third of the way to a fulfilling relationship in spite of pain!

Now, I'm not recommending you tell your partner a week into your relationship about every hospital admission you've had, although that question has actually slid into my inbox many times. ('Karra, when is the right time to tell my partner about my condition?')

I can't judge the right time for you, but you should ask yourself at some point in your long-term relationship if your partner understands everything about your health journey. Chronic pain tests you, and at some point it will change you and colour your life experiences differently. When that happens, your partner needs enough information to clearly see your chronic pain as separate from you — the incredible and valuable you.

The next chapter gives you the resources to do this essential groundwork with your partner, so you're both prepared to tackle pain together — hand in hand.

### Long and short

- » Research and experience confirm that chronic illness and pain are huge challenges for couples to navigate.
- » It's possible to achieve and sustain a remarkable relationship despite chronic pain.
- » Each 'remarkable' relationship is unique, but following the guidelines in this book can lead you there.
- » Getting on the same team as your partner is the first all-important step on the journey to remarkable.

# 2 On Pain

It is difficult for partners who have never experienced chronic pain to understand it. The fact that pain is invisible and many of us have no outward indication of its severity makes it quite complex. Your personal experience of pain adds to that complexity. So, before you sit down with your partner to share the details of your condition and pain, it helps to gain an understanding of the nature of pain itself, specifically the mechanisms of pain systems in your body.

### What is pain?

Let's start by looking briefly at key ideas about pain. To pay rent while studying for my masters, I taught anatomy to