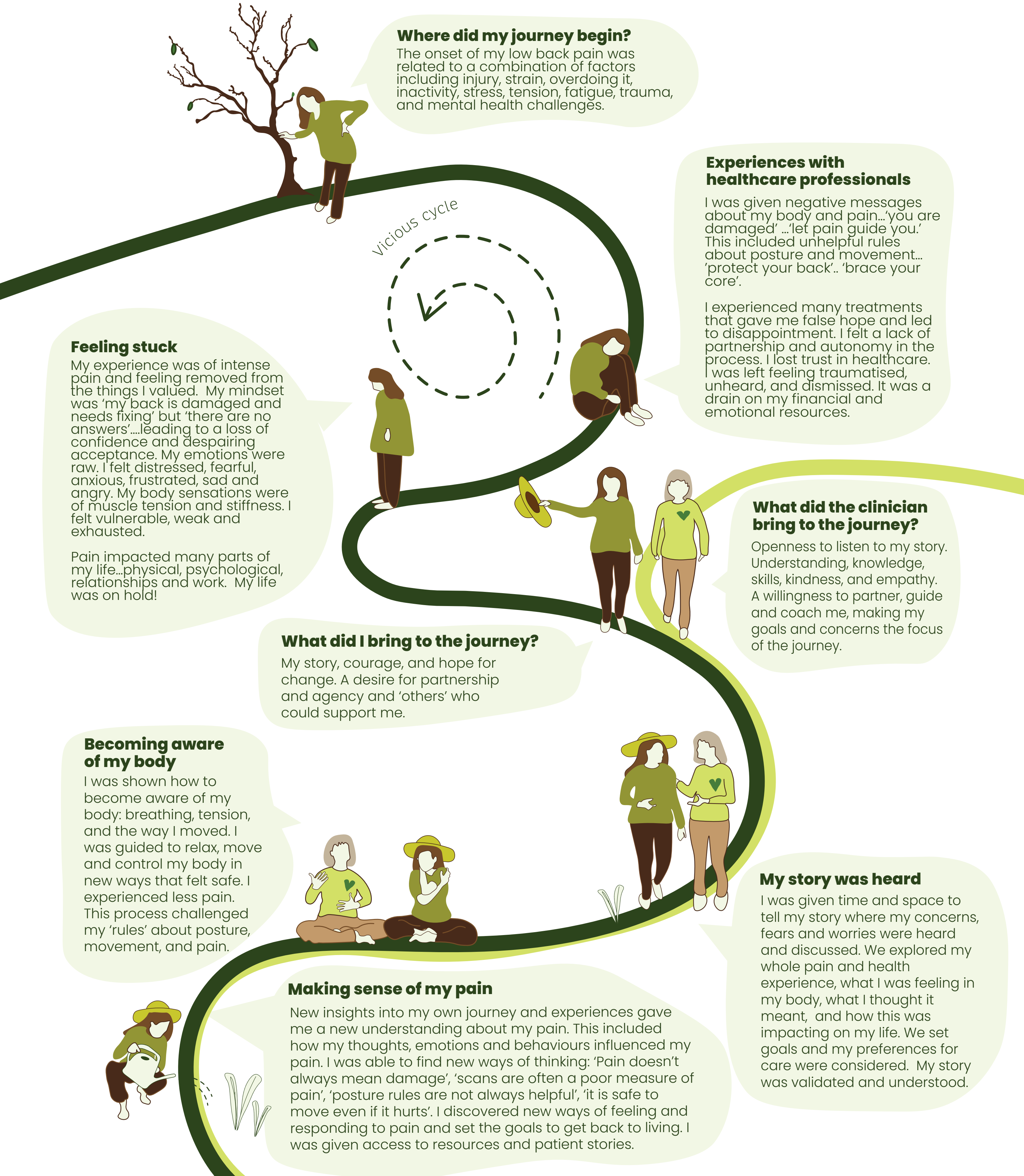
FROM DESPAIR TO LIVING AGAIN

People with disabling low back pain describe their journey through Cognitive Functional Therapy



Where did my journey begin?

The onset of my low back pain was related to a combination of factors including injury, strain, overdoing it, inactivity, stress, tension, fatigue, trauma, and mental health challenges.

Experiences with healthcare professionals

I was given negative messages about my body and pain…'you are damaged' …'let pain guide you.' This included unhelpful rules about posture and movement… 'protect your back'.. 'brace your core'.

I experienced many treatments that gave me false hope and led to disappointment. I felt a lack of partnership and autonomy in the process. I lost trust in healthcare. I was left feeling traumatised, unheard, and dismissed. It was a drain on my financial and emotional resources.

Feeling stuck

My experience was of intense pain and feeling removed from the things I valued. My mindset was 'my back is damaged and needs fixing' but 'there are no answers'….leading to a loss of confidence and despairing acceptance. My emotions were raw. I felt distressed, fearful, anxious, frustrated, sad and angry. My body sensations were of muscle tension and stiffness. I felt vulnerable, weak and exhausted.

Pain impacted many parts of my life…physical, psychological, relationships and work. My life was on hold!

What did the clinician bring to the journey?

Openness to listen to my story. Understanding, knowledge, skills, kindness, and empathy. A willingness to partner, guide and coach me, making my goals and concerns the focus of the journey.

What did I bring to the journey?

My story, courage, and hope for change. A desire for partnership and agency and 'others' who could support me.

Becoming aware of my body

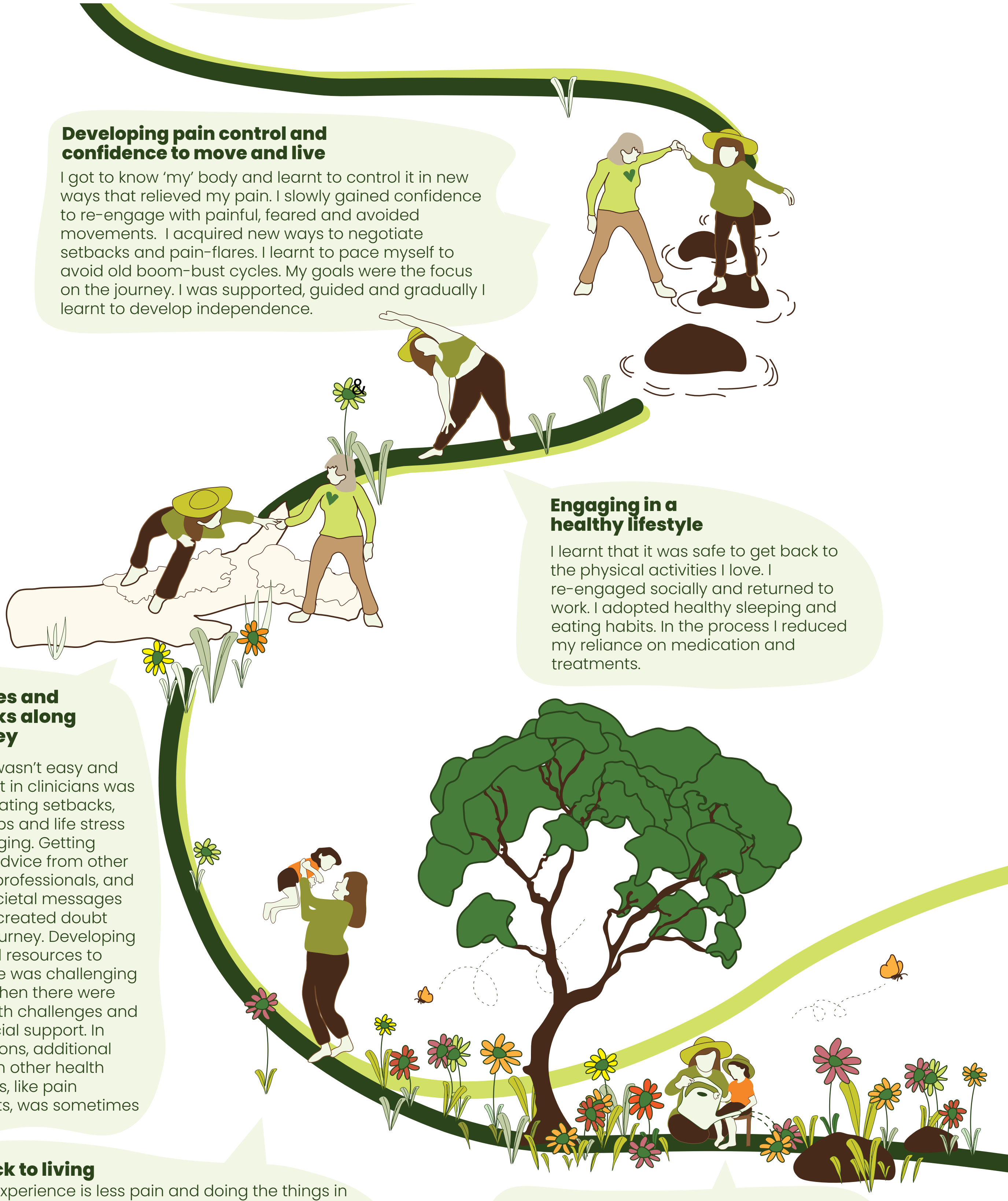
I was shown how to become aware of my body: breathing, tension, and the way I moved. I was guided to relax, move and control my body in new ways that felt safe. I experienced less pain. This process challenged my 'rules' about posture, movement, and pain.

My story was heard

I was given time and space to tell my story where my concerns, fears and worries were heard and discussed. We explored my whole pain and health experience, what I was feeling in my body, what I thought it meant, and how this was impacting on my life. We set goals and my preferences for care were considered. My story was validated and understood.

Making sense of my pain

New insights into my own journey and experiences gave me a new understanding about my pain. This included how my thoughts, emotions and behaviours influenced my pain. I was able to find new ways of thinking: 'Pain doesn't always mean damage', 'scans are often a poor measure of pain', 'posture rules are not always helpful', 'it is safe to move even if it hurts'. I discovered new ways of feeling and responding to pain and set the goals to get back to living. I was given access to resources and patient stories.



Developing pain control and confidence to move and live

I got to know 'my' body and learnt to control it in new ways that relieved my pain. I slowly gained confidence to re-engage with painful, feared and avoided movements. I acquired new ways to negotiate setbacks and pain-flares. I learnt to pace myself to avoid old boom-bust cycles. My goals were the focus on the journey. I was supported, guided and gradually I learnt to develop independence.

Engaging in a healthy lifestyle

I learnt that it was safe to get back to the physical activities I love. I re-engaged socially and returned to work. I adopted healthy sleeping and eating habits. In the process I reduced my reliance on medication and treatments.

Challenges and roadblocks along the journey

My journey wasn't easy and building trust in clinicians was hard. Negotiating setbacks, pain flare-ups and life stress was challenging. Getting conflicting advice from other healthcare professionals, and negative societal messages sometimes created doubt about my journey. Developing the personal resources to self-manage was challenging especially when there were mental health challenges and a lack of social support. In these situations, additional support from other health professionals, like pain psychologists, was sometimes needed.

Back to living

My experience is less pain and doing the things in life I value. My new mindset is 'pain is influenced by multiple factors'; 'I have tools to self-manage my pain'; 'It's a bumpy journey and takes time'. I have regained my sense of self and feel empowered. Emotionally, I feel calm and hopeful for the future. My body sensations have changed. I have re-connected with my body. I feel relaxed and confident to enjoy living without needing to protect my back.

I am engaging in valued activities... work, exercise, fun and socialising. Having ongoing support from the clinician during setbacks when needed is empowering.

Growth in other aspects of my life

As I gained control over my body and my pain, this expanded my sense of agency over other aspects of my life. I began to face other fears. In the process I developed and grew as a person.

The journey is different for everyone

For some it is quite quick (3-4 sessions over 12 weeks). For others it is slow, tough and full of setbacks, doubts and uncertainty (8 sessions over 6 months, and longer for some) with ongoing support if needed. The key is to keep on the journey and reach out for support when things get tough.

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1. Kent et.al., 2023. Cognitive functional therapy with or without movement sensor biofeedback versus usual care for chronic, disabling low back pain (RESTORE): a randomised, controlled, three-arm, parallel group, phase 3, clinical trial. The Lancet. https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(23)00441-5/abstract
2. O'Sullivan et.al., 2018. Cognitive Functional Therapy: An Integrated Behavioral Approach for the Targeted Management of Disabling Low Back Pain, Physical Therapy, https://doi.org/10.1093/ptj/pzy022

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