

PACING

Pacing took me a long time to learn. I'm a 51 yrs. old female with a husband and two adult children, and two dogs. I am recently retired but worked full time from 1990 until 2018. I've broken over 100 bones and had over 40 operations including a kidney transplant so I am familiar with chronic pain and trying to manage it.

One of the ways I have been repeatedly told to manage chronic pain is to pace my life, pace my activities, use pacing as a tool. It seems so straight forward to hear from a professional, but what does it mean and how do you consciously prepare to pace your life.

For me being told to pace your life is like being told to lose weight or stop smoking, it doesn't just happen, it's not easy and you have to keep working on it. It's something you need to be taught, practice and review. You don't wake up one day knowing how to pace, and you don't get it right 100% of the time.

Although it is something I am still working on, this is how I use pacing to manage my chronic pain.

Physical Pacing

Firstly, I plan out my week. This is broken down into the 'have to' and 'want to' activities. I put this into hourly slots and go through each day to understand what each day is going to look like.

I then use the Olympic Athlete's trick. I do a mental race of the day in my mind and think about what I have to do in detail and how I am going to feel at the end of the day and how that might impact on the following day. If I think the load of activities, I have planned are too many then I modify my timetable and build in more rest or sleep breaks, or times when I just need to put my feet up.

When modifying the planned activity for the day I don't always sacrifice the 'want to' activities for all the 'have to' activities in my life – that is no way to live. So sometimes I will try to move a non-essential appointment or medical test to another date so I can attend lunch at a friend's house (because doing both isn't possible). Or I will run my day as planned but let the family know I will not be able to help with dinner and will be going straight to the couch. This is how

I pace the known activities within life. Most of the time it works really well and I function with my pain at a manageable level with my mood good and my relationships intact. Of course, there are times when it falls apart but with this kind of pacing it is less frequent.

Then of course stuff comes up. I can probably plan for 40-50% of my life, but I have a family and friends and I want to be active in my world not stuck at home worried about pain. For instance, my friend recently bought me a pie maker recipe book as she knows I love cooking. I have a large pie maker but the recipe book was for the small pie maker. I was extremely excited and instantly wanted to give it a go and buy the smaller pie maker. This meant driving to Kmart, buying the smaller pie maker, coming home, and giving it a go – easy for someone without chronic pain.

But for me it involves changing the wheelchair battery in my car, if I am home alone then this risk experiencing pain. I then have to drive to the shops and hope for an appropriate disabled carpark, I have to unload the wheelchair, go to the shops, hope I can find and reach the pie maker, get it to the car and load it and the wheelchair back in the car and drive home and unpack it. Using the Olympic Athlete analogy again and thinking through each step and how it would feel, let me tell you, this is a lot for me. By the time I would be home there is no way I would have the energy to cook anything.

So, I compromise and pace. I ordered it online, I planned in my timetable roughly when it would arrive, what ingredients I would need, and when I would book myself time in my own kitchen to give it a go. It arrived within the week and I had a lovely time (with assistance) cooking chocolate mini cakes and vegetable frittatas for my family. Happy days.

So, this is how I pace. I think through each activity in small detail and how I am going to feel after it is completed and what that will mean. Sometimes it will mean a lot of pain and no activity for two days, but in some cases, like a friend's wedding, it will be worth it. At other times, like wanting the instant gratification of a pie maker, I decide it is not and plan differently.

Emotional Pacing

As well as planning for the physical side of pacing it is as important to manage the emotional aspects of pacing. This took longer for me to learn than the physical pacing. I'm sure we can all relate to being in fear of letting family and friends down with not being able to meet their expectations of what activity we are able to do. I have found myself in a situation where I feel I am constantly apologising for what I am not able to achieve or take part in.

Constantly apologising for one's failings is soul destroying and really comes about because of poor communication. Not communicating well enough what my limits and boundaries are to friends and family. So now I tend to be very clear about what I can and can't do. To be fair this has led to the loss of some friends and frustration with some family, but me apologising for that isn't going to change what I can or can't do.

For example, I physically can only do two activities a day. I can go out in the morning for brunch or lunch or a doctor's appointment, then need a rest so I can go out in the evening or have friends over. More than this and someone will be disappointed. So, I plan and communicate accordingly so other people who might be involved won't be disappointed.

The other important aspect of emotional pacing is forgiveness, primarily forgiveness of myself. This aspect in particular was a long time coming. To be able to accept that there are activities I can no longer participate in and be okay with that and forgiving myself has been very important.

Through reducing the anger and frustration towards myself for not being able to do things and by reducing the amount of apologising I do to others for the same limitations has made me happier and more productive. It has also made my family and friends more aware and accepting of my situation to the point now some of my friends know how to plan an activity with me in mind within my confines, which is really heart-warming.

Final Thoughts

In terms of pacing, I also take the advice of my family and my pain management team. I am an optimist and think anything is possible and sometimes overreach. My family now know how to pace with me and we will talk about a planned day out e.g., to the Central Coast and all the things we might plan for the day and often my husband or children will say, "Oh if we do that too that might be a step too far", so we will discuss it. Ultimately the pain I endure also impacts them too which I have learnt to be more sensitive too. Pacing your life to manage pain is not a solo activity.

My pain management team also assist with advice on correct medication, maximising my movement and nurturing my mind. All essential activities for proactive pain management and pacing.

I hope this helps you understand my ideas about pacing, to sum up: -

1. Plan your week, day by day and hour by hour
2. Understand your 'have to' activities and your 'want to' activities and don't just prioritise the 'have to' activities
3. Mentally imagine what you are going to feel like at the end of each day and see if you think you can tolerate the pain associated with it. If not, then adjust your schedule
4. Share your pacing ideas with your loved ones and carers and get their feedback
5. Pacing is not just a physical activity but also an emotional one. Stop apologising for your pain and communicate your circumstances and most importantly forgive yourself.