

I wish to submit a submission on the TGA paper for consultation on the regulation of autologous stem cell therapies:

My experience is simply as an individual who received a successful result from one-off stem cell therapy treatment on my knees. This took place after many years of pain and subsequent investigation of an alternative to the more invasive knee replacement surgery.

After arthroscopies on both knees some years ago which certainly gave me some relief, my surgeon warned me that down the track I would require a knee replacement. My osteoarthritis was quite severe. I am 71 and wanted to avoid heading down that path for as long as was possible so I began to research another option. My lifestyle had previously been an active one so the restrictions from the severe pain I was experiencing were impacting on my life in many areas. Going down any slope was incredibly painful (our home is situated on a steep slope) and most day to day activities were becoming increasingly difficult. My sleep pattern was disturbed because of the pain I experienced with any movement in bed. (This was validated by my Fitbit activity and sleep pattern tracker which plainly showed erratic and disturbed sleep) Driving a car involved pain in both hauling myself up into the drivers seat and alighting at my destination. My previously active holidays were heavily impacted in fact in every area of day to day life there were problems.

After much research and conversations with others who had sought relief from pain I made enquiries about stem cell treatment. I was only interested in receiving my own stem cells and after a number of conversations and correspondence with my chosen provider I booked my procedure for July 2014. I consider that I was fully informed that there was no guarantee of success - I could be a non responder. The risks were spelled out, the cost was not hidden and the entire procedure was explained to me in great detail. My hope was for less pain and more mobility. It was carefully explained to me about the pre and post op requirements and the importance of "doing the right thing" afterwards to give myself the best chance of maximising my results. I followed the instructions to the letter and the outcome has exceeded my wildest hopes. Although I am not completely pain free my pronounced limp has disappeared and the relief from pain is probably in the order of 80% (my assessment, not a scientific one). I can go up and down the many steps and stairs in my environment quite easily now, I can be out in my garden for many hours doing physical work (impossible before my treatment), I can sleep at night with few interruptions (according to my trusty Fitbit). Unexpected benefits - my 3 or 4 weekly breakouts of cold sores have ceased, my skin is clearer, my use of anti-inflammatories is minimal now and my whole outlook on life is better - I am not constantly thinking of pain before I put my feet to the ground.

The follow up contact has been regular since last July. Every 12 weeks I receive a phone call of some length to record my progress or otherwise in great detail. I believe this to be an important tool to gather patient information for the benefit of those who choose this path.

I do believe that there should be a record of adverse effects from the procedure - perhaps a national register - but do NOT believe there should be any changes to the present system which would make it more difficult for other people to access the treatment that I received.

Perhaps it is time for the Health Funds and Medicare to look at making the treatments more affordable to everybody rather than those who are fortunate to be able to take advantage of the therapy. Had there been a trial on offer I would have put my hand up in a flash to participate. I consider that the Health Care system would benefit from lesser numbers of people needing to use the hospitals, fewer medications required and less complications from invasive surgical options. No doubt these are necessary but in my case it will be a last resort if and when I need it.

Yours sincerely,

