Evaluating the Effects of the Jing Method™ of Clinical Massage on the Wellbeing of Adults Diagnosed with Ehlers-Danlos Syndrome or Hypermobility Spectrum Disorder.

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A dissertation submitted in partial fulfilment of the requirements of Jing Institute of Massage and Complementary Medicine for the Professional Diploma in Advanced Clinical Massage and Sports Massage

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"I certify that this work has not been accepted in substance for any degree and is not concurrently being submitted for any degree other than that of the Diploma in Advanced Clinical Massage and Sports Massage being studied at Jing Advanced Massage Training. I also declare that this work is the result of my own investigations except where otherwise identified by references and that I have not plagiarised the work of others".

Jessica Janneman

Date: 10 March 2026

ACKNOWLEDGEMENTS

This study was always about telling part of the story of a community that has long been misunderstood. It was about providing hope and a way forward for these wonderful people and also for the massage therapists wanting to help and wondering how. I truly believe this work can be part of a bigger conversation, in which we have a key role to play, and that this is actually just the start.

None of this would have been possible without the support of so many people, too many to mention really, for which in itself I am incredibly lucky.

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My dad, who I wish could have seen it

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ABSTRACT

BACKGROUND

The Ehlers-Danlos Syndromes (EDS) and Hypermobility Spectrum Disorder (HSD) are heritable disorders of the connective tissue. They are multi-systemic in their presentation which makes them difficult to diagnose and treatment options hard to access. Symptoms vary significantly, further compounding these issues, and affecting the overall quality of life of the people living with these conditions. This study seeks to evaluate the effects of the Jing Method™ of clinical massage on the wellbeing of adults diagnosed with Ehlers-Danlos Syndrome or Hypermobility Spectrum Disorder.

METHOD

Thirteen people were recruited and ten completed a 16-week study comprising six control weeks, six intervention weeks, and a follow-up at week 16. Participants were all female, aged over 18 and had a formal diagnosis of EDS or HSD. Participants completed the Pain Outcomes Questionnaire (short form) weekly during weeks 1-12 and once again at week 16. The intervention was a 45-minute hands-on treatment, which was based on the Jing Method™ Stress and Chronic Pain Protocol, with a taught self-care element for completion at home that included breathwork, acupressure and movement.

RESULTS

This study showed a total impact reduction of 25.1% from the start of the control to the end of the intervention period, with decreases in all categories as measured by POQ.

The follow up questionnaire at week 16 showed a slight decrease in total impact without treatments for four weeks, though still indicates an 18% reduction from week 1 of the study.

CONCLUSION

The downward trajectory of the POQ scores across all categories of the questionnaire shows the positive impact on wellbeing in the participant group following six weeks of hands-on treatment combined with at home self-care. The results at week 16 (following a gap of four weeks since last treatment) demonstrate that the benefits remained after the sessions had finished.

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LITERATURE REVIEW

There are currently no National Institute for Health and Care Excellence (NICE) guidelines for the treatment of adults diagnosed with the Ehlers-Danlos Syndromes (EDS) or Hypermobility Spectrum Disorder (HSD). Diagnostic journeys are often fraught and, even with the validation that a diagnosis can bring, lack of knowledge around treatment options can have a detrimental effect on an individual's wellbeing. This review of recent literature seeks to consider how the Jing Method™ of clinical massage may play a role in the management of these conditions.

EDS and HSD are heritable connective tissue disorders. These are symptomatic disorders as distinct from generalised asymptomatic joint hypermobility (where a joint has a greater range of movement than the average), which affects around 30% of the population (The Hypermobility Syndromes Association, 2025). Of this group around 10% are estimated to have symptomatic hypermobility (of which EDS and HSD are two disorders) affecting multiple body systems with varying severity (The Hypermobility Syndromes Association, 2025).

This distinction is important in management, education and the avoidance of over-medicalisation (Nicholson et al., 2022). Prevalence of EDS/HSD is hard to account for accurately as the diagnostic process is challenging (Russek, Simmonds and Stott, 2019; Bennett et al., 2021; Francomano et al., 2023), though the imminent review of criteria (The Ehlers-Danlos Society, 2025) aims to improve education, diagnostic process and ultimately care.

The 13 subtypes of EDS, with the exception of hEDS (hypermobile type), are diagnosed by genetic testing. HSD shares many symptoms with hEDS and is diagnosed when the hEDS diagnostic criteria aren’t fully met. HSD is no less challenging to live with than hEDS and people with these conditions should be afforded the same level of care, understanding and belief (Nicholson et al., 2022).

It should be noted that while hEDS is the most common of the Ehlers-Danlos syndromes and currently classed as rare, the other subtypes are mainly ultra-rare and receive even less in terms of understanding (The Ehlers-Danlos Society, 2026). Prominence of joint hypermobility across the subtypes is variable. The multisystemic nature of these conditions is exemplified by Table 1, which records the symptoms of hEDS/HSD. Symptoms of all other subtypes can be found on The Ehlers-Danlos Society website (2026).

Table 1: Signs and Symptoms of hEDS and HSD

(Adapted from Russek, Simmonds and Stott (2019), with information from: Chopra et al., 2017; Malfait et al., 2017; Tinkle et al., 2017; Alsiri et al., 2020; Tinkle, 2020; Bennett et al., 2021; Pearce et al., 2023; Chuchin and Ornstein, 2024; Clarkson University, 2025).

System Affected	Health Issues
Musculoskeletal	• Instability, frequent sprains, subluxations, dislocations • Chronic joint pain, osteoarthritis, temporomandibular joint dysfunction, foot dysfunction • Gait impairment • Scoliosis • Possible decreased bone density, although evidence for this is mixed, according to Tinkle et al (2017) • Tendinitis, bursitis, synovitis, tenosynovitis, fasciitis, tendon ruptures • Trigger points, muscle spasm, muscle strain, deconditioning • Some periodontal issues (although not to be confused with periodontal EDS which is early onset and involves widespread tooth loss), dental crowding or high/narrow palate
Autonomic	• Dysautonomia: Orthostatic Hypotension and/or Postural Orthostatic Tachycardia Syndrome (POTS) presenting with: tachycardia, dizziness, presyncope/syncope, anxiety, chronic fatigue, sleep disorder, exercise intolerance, dependent edema, purpling skin, temperature dysregulation/heat intolerance, brain fog, trouble concentrating • Raynaud Syndrome
Cardiovascular	• Varicose veins • Mitral valve prolapse or aortic dilatation (not common) • Pelvic congestion syndrome • Median arcuate ligament syndrome • Superior mesenteric artery syndrome • Dysautonomia, POTS
Neurological	• Motor delay (in children), developmental co-ordination disorder • Proprioceptive, interoceptive and motor control deficits leading to clumsiness, poor balance, frequent falls, trips or bumping into things • Fibromyalgia/central sensitisation, hyperalgesia • Headaches, migraines, dizziness • Cervico-medullary syndrome/myelopathy

	• Chiari malformation, Tarlov cysts, CSF leaks, idiopathic intracranial hypertension • Paraesthesias and nerve compression disorders, tethered cord • Restless leg syndrome • Pseudo-seizures, syncope • Central sensitisation • Resistance to anaesthesia
Neurodevelopmental, Cognitive and Mental Health	• Motor delay (in children), developmental co-ordination disorder • Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Tourette Syndrome • Interoceptive disorders • Anxiety and panic disorder • Fear of movement, kinesiophobia, pain catastrophising • Memory, concentration or processing problems, brain fog • Depression • Medical PTSD
Gastrointestinal	• GORD, irritable bowel syndrome, constipation or diarrhoea, nausea/vomiting, bloating, abdominal pain, gastroparesis, food sensitivities • Gastroesophageal reflux, chronic gastritis, heartburn • Prolapsed rectum, diverticulitis, colitis • Hernias (all types)
Urogenital and gynaecological	• Urinary incontinence • Prolapsed bladder or uterus • Pelvic floor disorders • Urinary tract infections • Interstitial cystitis • Dysmenorrhea, endometriosis, adenomyosis, vulvodynia, pelvic pain, painful intercourse • Pregnancy complications – higher incidence of: pre-eclampsia, eclampsia, pre-term births, pre-term rupture of membranes, ante/post-partum haemorrhage, hyperemesis gravidarum, shoulder dystocia, caesarean wound infection, postpartum psychosis, PTSD, precipitate labour
Immune	• Mast Cell Activation Syndrome (MCAS): hives, flushing, chemical and environmental sensitivities, medication and food sensitivities, fatigue, trouble concentrating, migratory pain, excessive inflammatory response, anxiety
Dermatological and Haematological	• Hyperextensible and fragile skin • Slow healing or scarring, poor wound healing, excessive bleeding

	Easy bruising Piezogenic papules MCAS skin issues Excessive menstrual bleeding, gastrointestinal bleeding, hematomas, hemarthroses
Respiratory	Costochondritis Slipping ribs Dysfunctional breathing, vocal cord dysfunction Pectus excavatum
Other	Insomnia, sleep disturbance, debilitating chronic fatigue

Referred to as a ‘diagnostic odyssey’ (Halverson et al., 2021), often there is more than a decade before diagnosis, which has a significant impact on quality of life (Hakim, Tinkle and Francomano, 2021). The journey to, and even beyond diagnosis is often reported to be one of belittling, gas-lighting and disbelief which, unsurprisingly, leads to poor patient-provider relationship and poor medical outcomes (Bovet, Carlson and Taylor, 2016; Bennett et al., 2021; Clark et al., 2023; Francomano et al., 2023).

Conventional Treatments

Whilst there is currently limited research into treatment options for EDS/HSD (Bovet, Carlson and Taylor, 2016; Russek, Simmonds and Stott, 2019), the complex and multisystemic nature of these conditions lends them to a multidisciplinary, multimodal approach (Song et al., 2020; Nicholson et al., 2022; Clark et al., 2023). More specifically the use of movement is acknowledged throughout the literature (Russek, Simmonds and Stott, 2019; Buryk-Iggers et al., 2022; Slicaru and Cerchez, 2023; Eichinger et al., 2025).

The need for specialist knowledge is emphasised particularly when considering associated co-morbidities (Russek, Simmonds and Stott, 2019). Eichinger et al. (2025) suggests that earlier engagement with specialist physiotherapy brings better compliance and benefit than with non-specialist practitioners. Buryk-Iggers et al. (2022) similarly find a direct correlation between the length of the specialist exercise and rehabilitation relationship and strength gains.

Ill-informed physiotherapy/exercise protocols are shown to cause harm to patients, both physically through injury and also psychologically by reducing trust in their ability to exercise (Clark, Khattab and Carr, 2014; Bovet, Carlson and Taylor, 2016; Bennett et al., 2021; Halverson et al., 2021; Chuchin and Ornstein, 2024). If we consider the consequences of such deconditioning for overall strength and joint stabilisation, alongside the mental health benefits of exercise it is evident that a lack of engagement with movement has a detrimental effect on quality of life (Buryk-Iggers et al., 2022).

In addition to the physical benefits of a specialist physiotherapy intervention, Bennett et al. (2021) recognise the hope that such relationships can bring for the EDS/HSD patient. Occupational Therapy strategies such as bracing, splinting and taping have, in some instances, been found to be beneficial (Song et al., 2020; Engelbert et al., 2017).

Surgical interventions and pain medications are evidenced in the literature (Chopra et al., 2017; Russek, Simmonds and Stott, 2019; Eichinger et al., 2025), as are recommendations for the specific manifestations of the comorbidities (Mathias et al., 2021; Ruiz Maya et al., 2021). This extends beyond the scope of this literature review, which is necessarily limited to a more generalist patient wellbeing; though, of course, the contribution to this of managing these comorbidities should not be underestimated.

While the specificity of specialist knowledge is clearly important, the recommendation of a multidisciplinary approach suggests a need for communication between specialisms to provide an integrated package of care (Clark et al., 2023; Francomano et al., 2023) rather than the patient themselves becoming a go-between. Furthermore, if this is considered through the lens of diagnostic experience, in conjunction with findings below on therapeutic alliance, the lack of psychosocial consideration within current care becomes apparent, as does the reason for which this may be crucial in improving wellbeing within this community.

Complementary Approaches

A multimodal approach combining both conventional and complementary modalities (Bovet, Carlson and Taylor, 2016; Song et al., 2020; Doyle and Halverson, 2022; Guedry et al., 2023; Desroches, 2024) is well supported in both EDS/HSD care and improved wellbeing more generally. These sources explore a multitude of complementary/alternative modalities through the spectrum of presentation across the EDS/HSD community. Variability of symptoms within one individual also means that no one single approach should be considered definitive (Song et al., 2020).

In some multimodality studies (Song et al., 2020; Demes, McNair and Taylor, 2020; Guedry et al., 2023; 2024) massage has been reported as playing an effective role in care of the EDS/HSD individual. These studies had variable cohort sizes (98, over 500, 353 respectively) though all form substantial groups. It should be noted that Song et al. (2020) is a retrospective cohort study drawing from the records of patients seen in one practice across a period of four years and therefore lacked direct impact from the patients who were not randomised. The other, larger-scale studies are self-selecting in that the participants answered advertisements to take part, which will bring a bias to the data. Little is specified here about style of massage, but Song et al. (2020) find myofascial release and heat to be of particular benefit while Russek et al. (2019) advocate for the use of trigger point work and mobilisation within a physiotherapy setting.

Slicaru and Cerchez (2023) consider the impact of massage on a person with EDS/HSD's overall quality of life (rather than solely on the tissue), which is more broadly explored by Kerry et al. (2024). This is important to consider within the context of diagnostic pathway and medical experience previously discussed and the idea of therapeutic alliance below.

Stewart-Richardson et al. (2024) call for more evidence-based research in massage and consider the difficulties in achieving this due to the nature of the work. There is, however, evidence of reluctance to engage with massage therapy within the EDS/HSD community, with fear of it causing pain (Halverson et al., 2021) and the sense of it being a 'passive' intervention (Di Bon, 2025).

Desroches (2024) identifies the use of massage as a way of lowering fear of movement within the context of chronic pain management more broadly and therefore encouraging people back to movement. If we consider this with regard to the discussion on exercise rehabilitation above there is an important interplay between conventional and complementary therapies that could have a positive outcome on an individual with EDS/HSD and their wellbeing.

The Jing Method™

The Jing Method™ is an outcome-based, clinical massage therapy framework. Designed by Rachel Fairweather and Meghan Mari, it is a fusion of eastern and western techniques which are combined to treat chronic pain (Fairweather and Mari, 2015). Integral to The Jing Method™ is the understanding of pain as a biopsychosocial (BPS) experience (Fairweather and Mari, 2015). Figure 1 below makes clear how this translates to an EDS/HSD community.

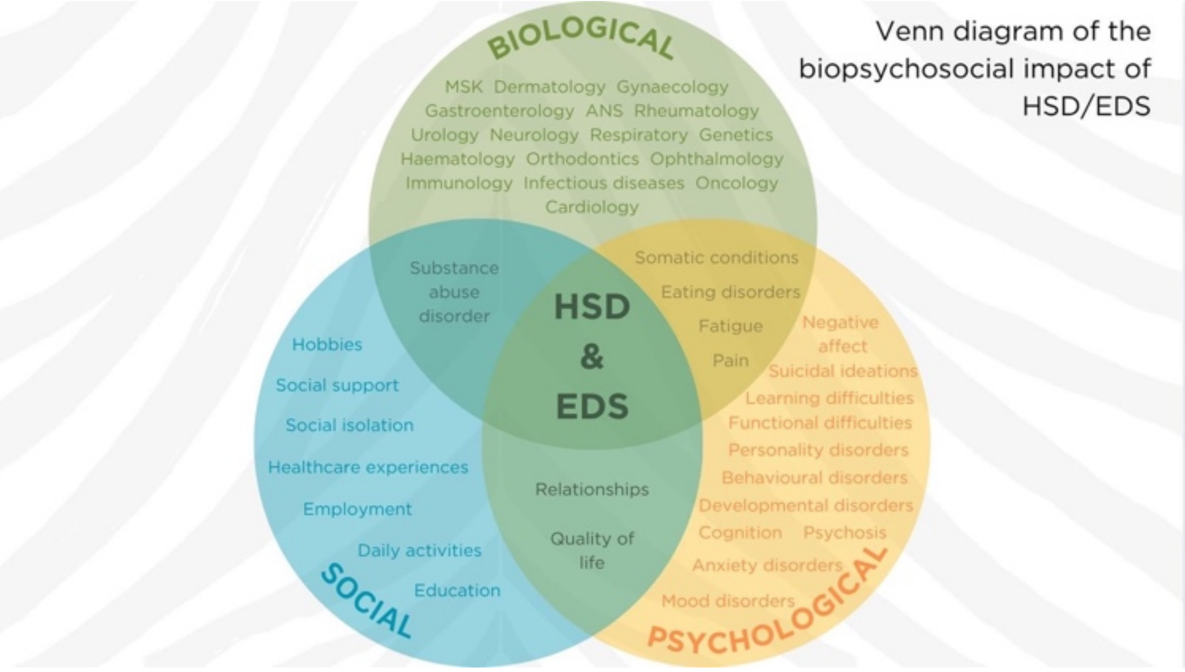

Figure 1: Venn diagram of the biopsychosocial impact of HSD/EDS (Clark et al., 2023).

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To appreciate these factors, an emphasis must be placed on consultation, which Russek et al. (2019) highlight and is an integral part of the Jing Method™. It is here that a therapeutic alliance begins between practitioner and client. For a population that historically may have had a fractious relationship with professionals, this is crucial, particularly when seen as correlating with positive outcomes (McParlin et al., 2022; Desroches, 2024). Lack of trust in practitioner education plays a role (Bovet, Carlson and Taylor, 2016) in light of the previous discussion around mismanagement of these conditions.

So important is the therapeutic alliance in person-centred care that it, alongside a BPS approach, should be integral in approaches with EDS/HSD (Guedry et al., 2024). Bennett et al. (2021) found that often it was not that a treatment had worked, but that healthcare professionals had taken the time to listen compassionately and empathetically to patients. The impact of a positive therapeutic relationship on the outcomes of EDS/HSD patients is an area to be further explored. Its effect has been researched on low-back pain sufferers being treated with the Jing Method ™ by Gillingham (2017) which found that a positive therapeutic alliance can help reduce pain and fear and improve vitality .

The cornerstone of the Jing Method™ treatment approach is summarised by the HFMAST (Heat, Fascial Techniques, Muscles, Acupressure, Stretching, Teaching) mnemonic. Table 2 offers evidence as to how each element is situated within an EDS/HSD context.

In addition, previous studies using the Jing Method™ to evaluate its effects on wellbeing in adults have been drawn on in preparation for this study and demonstrate, albeit using different instruments for different systemic chronic pain conditions, its efficacy (Birch, 2024; Dawe, 2024; Snook, 2024).

This study also continues the work of Drew (2024), who researched the effect of the Jing Method ™ on joint pain in people with hypermobility. This study considers wellbeing more broadly, incorporating joint pain alongside other issues of hypermobility as component factors for adults diagnosed with EDS or HSD. While different, this study is undoubtedly informed by her work.

Table 2: Jing Method™ HFMAST in relation to EDS/HSD management

H-the use of Heat (hot or cold)	Song et al. (2020.) find heat to be beneficial for the EDS/HSD population. Lee, Park and Kim (2011) look at the impact of heat and massage on the autonomic nervous system.
F-the use of Fascial techniques: both direct and indirect methods.	Wang and Stecco's research (2021) demonstrates abnormalities in fascial glide, thickness, tissue stiffness, tendon elongation and myofibroblast activation in the EDS/HSD population (Wang et al., 2023; 2025). Song at al. (2020) find myofascial release to be of particular benefit.
M-treating Muscles with precise trigger point therapy	Russek, Simmonds and Stott (2019) suggest trigger point work could be useful though the Jing Method™ itself suggests this is done sparingly (Fairweather and Mari, 2015).
A-treating relevant Acupressure points	Ghanbari et al. (2022) and Lin et al. (2022) demonstrate the use of acupressure from both chronic pain and mental health perspectives though evidence of EDS/HSD specifically is lacking.
S-Stretching	Song et al. (2020) suggest stretching as beneficial in reducing muscle spasms in this community. There is fear around stretching due to the already increased ROM and laxity within the joints. Little has been written about stretching and EDS/HSD specifically but Yin et al. (2025) looks at the use of Proprioceptive Neuromuscular Facilitation (PNF) in ankle stability and this should be considered.
T- Teaching the client self-help strategies that lie within the therapist's scope of practice.	Guedry et al. (2024) suggest outcomes are improved with the integration of self-care as a part of a treatment package.

Summary

This literature review is clear that positive therapeutic alliance and the understanding of pain as a BPS experience are integral to the management of EDS/HSD. It also demonstrates that specialist physiotherapy/movement knowledge can promote positive outcomes in this population.

In understanding the components of the Jing Method™ it is evident that these elements fit firmly within its scope. Arguably more specialist knowledge of EDS/HSD may be needed for rehabilitation work, but this is somewhat lacking in the research currently. Education around the active (rather than passive) approach that Jing clinical massage takes is necessary as is further research into which massage techniques may be of particular benefit, though Wang et al., (2025) researching fascia in the EDS/HSD person, suggest findings around the efficacy of fascial techniques may be of particular interest (The Ehlers-Danlos Society, 2025).

METHOD

Ethical approval was received from the Jing Institute of Massage and Complementary Medicine (see Appendix A). The study is to investigate the efficacy of the Jing Method™ of Clinical Massage on the wellbeing of adults diagnosed with Ehlers-Danlos Syndrome or Hypermobility Spectrum Disorder, through a series of six hands-on massage treatments combined with self-care exercises.

Participants

A group of 22 people answered an advertisement placed on Instagram, Facebook and in WhatsApp groups. They expressed interest by completing a survey on JotForm which checked inclusion and exclusion criteria (inclusion being people over 18 with a diagnosis of EDS/HSD from a medical professional and exclusion if a current pregnancy, surgery within the previous 8 months, an additional medical condition unrelated to EDS/HSD, an intention to start new treatment/intervention during the study period). 17 were eligible and 13 then progressed to a Zoom consultation during which medical history was taken, the study was further explained and consent obtained (consent form returned via email see Appendix C). Participants were anonymised by assigning each a number and data was all stored securely through my booking system which is accessible only by password and fully adheres to GDPR. These were all women aged 19- 52. One participant withdrew from the study before their first hands-on treatment for health reasons. All had been made aware that they could withdraw at any point during the study without explanation.

Study

This study used a ‘within subjects design’ as this reduces variability across individuals in a small group. It used the Pain Outcomes Questionnaire Short Form (Clark and Gironda, n.d.) as its validated instrument. The POQ was developed for the Chronic Pain Rehabilitation Program at the James A. Haley Veterans Affairs Hospital in Florida. It comprises 20 questions that assess pain, mobility, activities of daily living, vitality, negative affect and fear, which it was felt best measured the idea of wellbeing within the EDS/HSD community (see Appendix D). This questionnaire was distributed electronically every Monday during the Control Period (weeks 1-6), then five days after treatment in the Intervention Phase (weeks 7-12).

Intervention

Weekly 60-minute sessions over six weeks were conducted in person and followed the same format of a few minutes check-in on previous week, findings from self-care etc. This was followed by a 45-minute hands-on treatment, which was an abridged version of the Jing Method™ Chronic Stress & Pain Protocol (Fairweather and Mari, 2015: 355-369) involving AMMA, heat, myofascial release, acupressure, PNF stretching. The protocol (see Appendix E) remained the same for each client and for each week and was designed to be appropriate for the spectrum of mobility and needs of all participants.

At the end of the session in weeks 7, 9 and 11, a 10-minute self-care routine was taught. It was recorded and distributed to participants (see Appendix F) for use at home three times per week. The exercises included breathwork, acupressure points and proprioceptive work which were designed based on the participant group and findings from the review of recent literature. Participants were asked for feedback on the self-care, including compliance, at the start of the following session.

The POQ was then distributed in Week 16 (following a 4-week period without intervention) along with an optional feedback sheet (see Appendix H) to gather data on the longer-term effects of the treatment.

RESULTS

A total of 13 participants were recruited to join the study, 10 people completed the process and three withdrew during the intervention stage.

Results presented represent this study of 10 participants (Janneman, 2026) alongside the combined data of 28 participants (Andrews, Ells and Janneman, 2026) who conducted parallel studies.

The scoring template of the POQ (see Appendix D) uses the 20 questions asked weekly to interpret numerical scores into categories:

Table 3: POQ categories

CATEGORY	MAXIMUM SCORE
Pain (pain intensity)	**10**
Mobility (pain-related impairment of mobility)	**40**
Activities of Daily Living (pain-related impairment in completing ADLs)	**40**
Vitality (impairment in activity and energy levels)	**30**
Negative Affect (dysphoric affect and associated symptoms)	**50**
Fear (pain-related fear and avoidance)	**20**
TOTAL IMPACT	**190**

Results presented show Control Period (weeks 1-6) in green, Intervention Period (weeks 7-12) in yellow and week 16 questionnaire results (also green) to indicate longer-term effect. They combine individual participants' data to create a mean average.

TOTAL IMPACT

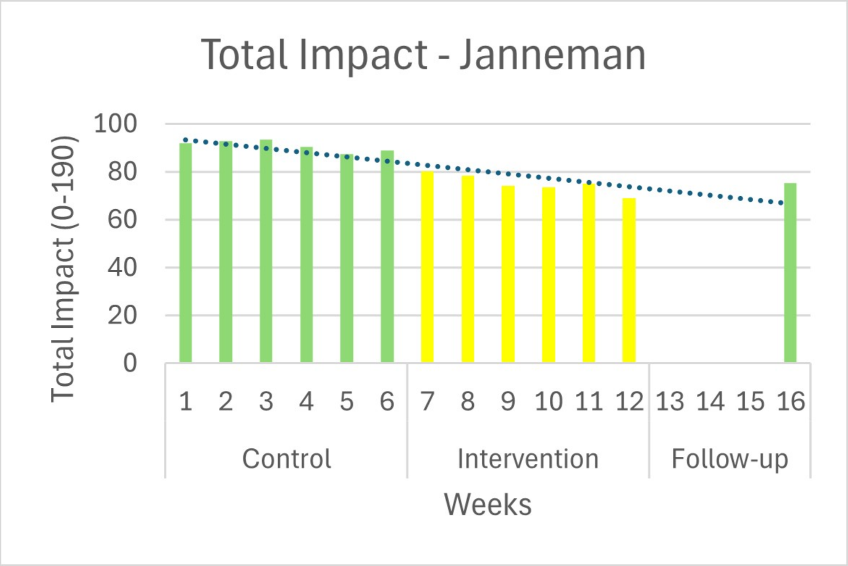

Figure 2: Total Impact - Janneman data. Weeks 1-12 - 25.1% reduction. Weeks 1-16 - 18% reduction.

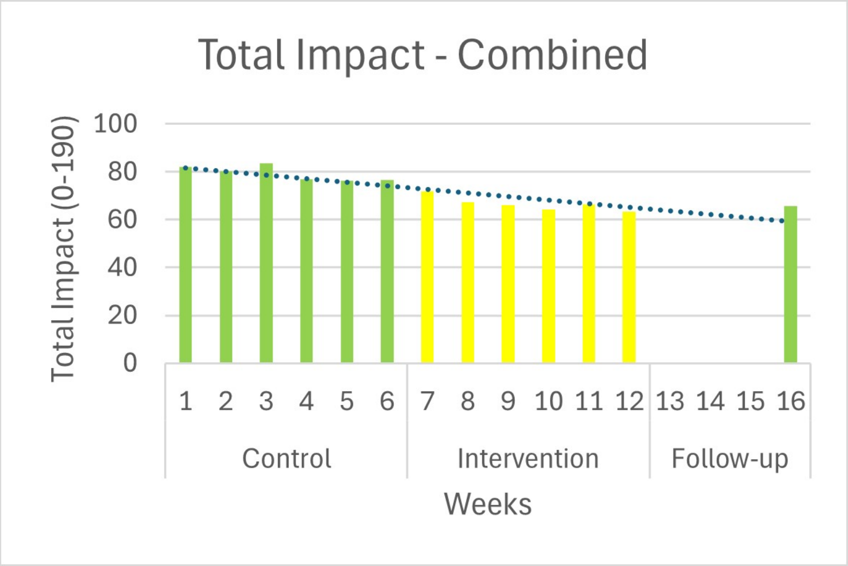

Figure 3: Total Impact - Andrews, Ells and Janneman data. Weeks 1-12 - 23% reduction. Weeks 1-16 - 20% reduction.

Figures 2 and 3 indicate an overall trend in decrease of symptoms from week 1 to week 12 across both individual and combined studies. Interestingly in both samples the total impact at week 16 returns to a level that is roughly on par with week 11, therefore suggesting the longer-term impact of such treatment and that even without treatment for four weeks, the overall impact does not regress rapidly.

Table 4: Total Impact scores (mean averages max. 190).

	Janneman	Andrews, Ells, Janneman
Week 11	75	66.4
Week 12	68.8	63.3
Week 16	75.4	65.7

PAIN INTENSITY

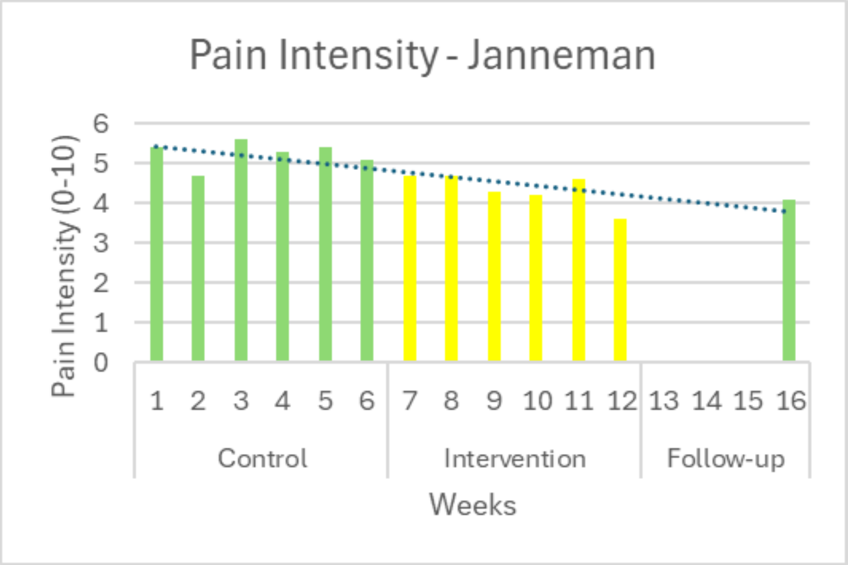

Figure 4: Pain Intensity – Janneman data. Weeks 1-12 - 33.3% reduction. Weeks 1-16 24% reduction.

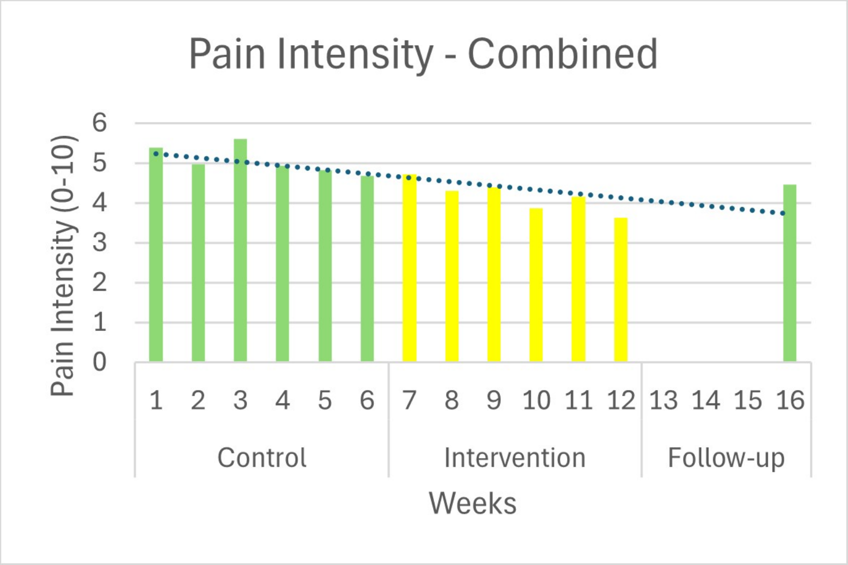

Figure 5: Pain Intensity – Andrews, Ells and Janneman. Weeks 1-12 - 32.7% reduction. Weeks 1-16- 17.2% reduction.

The correlation in reduction of pain across both data sets in Figures 4 and 5 is in concurrence with Drew (2024) who found a 40% reduction in pain from weeks 1-12.

NEGATIVE EFFECT

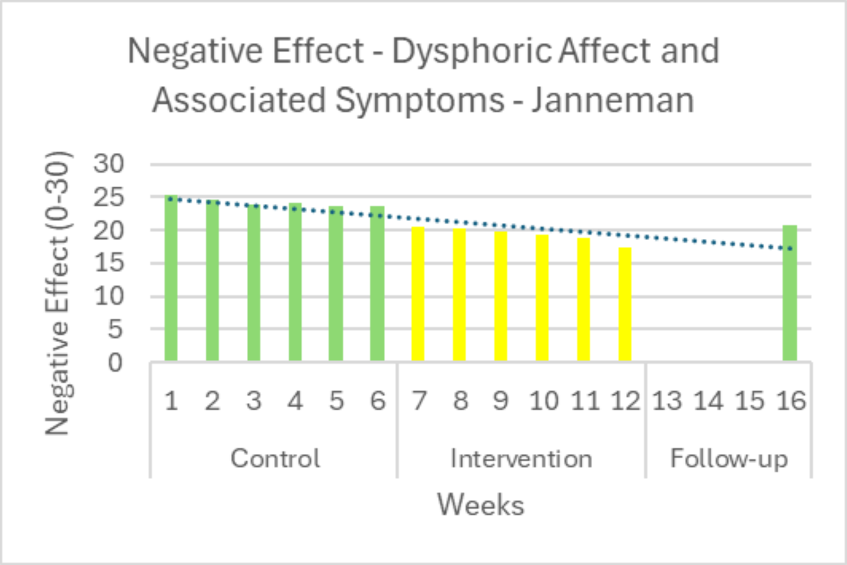

Figure 6: Negative Effect – Janneman – weeks 1-12 – 31.5% reduction. Weeks 1-16 - 18.1% reduction.

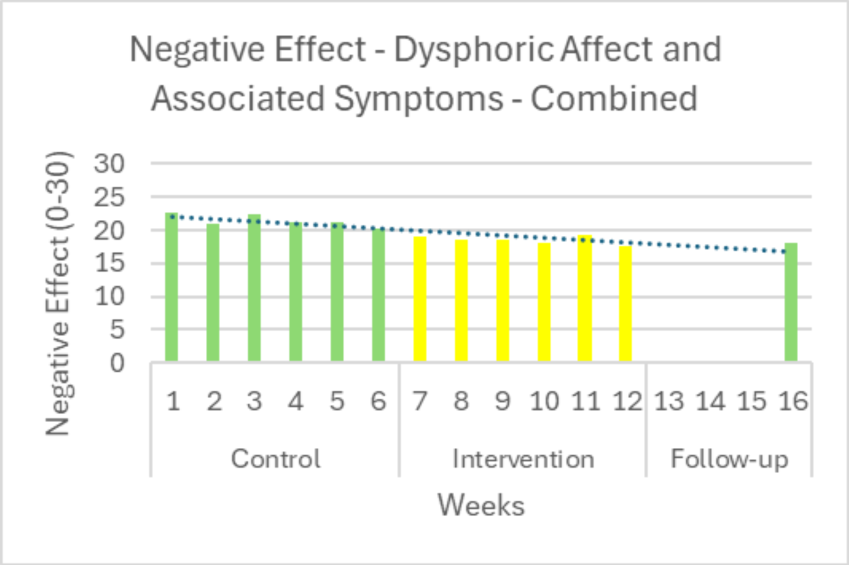

Figure 7: Negative Effect – Andrews, Ells, Janneman – weeks 1- 12 – 22.1% reduction. Weeks 1-16 – 20.3% reduction.

While still in tandem, the sharper change in this study data versus the collective data at week 16, is likely to be a reflection of individual participants' personal experiences within this period (for instance whether they continued with the self-care, sickness etc.).

The results highlighted here have been selected as they particularly reflect the broader impact on wellbeing considered within this study. All further results from the POQ data can be found in Appendix G.

DISCUSSION

KEY FINDINGS

This study appears to indicate that the Jing Method™ of Clinical Massage may positively affect the wellbeing of adults living with Ehlers-Danlos Syndrome or Hypermobility Spectrum Disorder. The results show a reduction in all measures in the POQ questionnaire from Weeks 1-12 and a sustained reduction without intervention at Week 16. Its findings are corroborated by the parallel studies of Andrews (2026) and Ells (2026) and are also in line with Drew's (2024) study into pain reduction within the hypermobile community, which further supports the results.

OBSERVATIONS & LEARNINGS

Pain vs Wellbeing

While this study considered participants' wellbeing overall, they reported pain reduction as a primary intention for taking part. The choice of the researcher not to focus solely on pain resulted from the desire to consider the broader nature of these conditions, though its inclusion within the POQ (in four of the six categories) acknowledges how a reduction in pain may contribute to overall wellbeing, which is apparent in the findings.

This study found that as pain intensity from weeks 1-12 reduced by a third (33%), there was a concurrent reduction in pain-related fear and avoidance (21.7 %). Consequently, impairment of mobility decreased by 24.1%, and impact on activities of daily living reduced by 20%.

Alongside this came a drop in impairment of activity and energy levels by 21.9% and dysphoric effect was reduced by 31.5%. The interplay between these results may substantiate Buryk Iggers et.al.'s (2022) findings that lack of movement can have a detrimental effect on quality of life and demonstrates the impact that it has on wellbeing overall.

Massage to Movement

In consideration of the importance of movement here, we can see the role that the Jing Method™ may play in introducing movement to this community. This takes us away from ideas of massage as 'passive' treatment (Di Bon, 2025) and further demonstrates its role in encouraging the return to movement for sufferers of chronic pain as found by Desroches (2024). Moreover, participants have seemingly benefitted from self-care/movement that is designed to be specific to the EDS/HSD community (Eichinger et al., 2025; Russek et al., 2025) rather than a more general approach.

Self-care

Reported adherence to the self-care element of the study was good during the intervention phase, though difficulties with making time and problems engaging with the breathwork were mentioned (see feedback forms – Appendix I). It is pleasing to see some participants find the benefits, though more consideration of the challenges of a breathwork practice and appropriate adaptations – particularly for the participants with an ADHD diagnosis (of which seven had formal diagnoses) – may have been beneficial. The treatments enabled some participants to explore what relaxation felt like in their bodies, which they were then able to further explore in the self-care. Some recognised the positive impact of this relaxation in their feedback, which perhaps was evidenced by the reduction in negative dysphoric affect (31.5% weeks 1-12).

Components of the Jing Method™

Myofascial Release techniques (components of the Jing Method™) are suggested to be particularly beneficial by Song et al. (2020) and were prominent in the treatment protocol. Research into abnormalities in fascial glide, thickness, tissue stiffness, tendon elongation and myofibroblast activation in the HSD/EDS population (Wang and Stecco, 2021; Wang et al., 2023; 2025) all offer preliminary evidence as to why the Myofascial Release components of this protocol may have contributed to the findings in this study.

The power of positive therapeutic alliance that is integral to the Jing Method™ (Fairweather and Mari, 2015) and researched by Gillingham (2017) is considered to be of particular importance in the care of people with EDS/HSD (Russek, Simmonds and Stott, 2019). The participants corroborate this in their feedback, using phrases such as feeling ‘validated’, ‘heard’ and part of a ‘community’. Its impact may have influenced all POQ outcomes as this relationship is integral, not only to the effectiveness of the treatment itself, but also to compliance with the self-care.

The researcher’s own EDS diagnosis, which participants were aware of, may have contributed to the therapeutic alliance, but brings a potential bias that should be acknowledged.

LIMITATIONS

Validated Instrument

A number of participants commented on the problems of the POQ as the measure. They found it difficult to know how to report a previous week when their day-to-day experience can be very different. There was also a concern over whether the questions really reflected the benefits that they were finding and clearly wanted to be acknowledged (which may in turn have influenced their results). For instance, the POQ omits any consideration of resilience, which some participants felt they had gained, noting that they were generally more able to cope with their symptoms and flares. There are of course inaccuracies that can occur when self-reporting both in the recording itself and in interpretation. It may have been useful to include a box to report self-care and a free-text box for other comments. There may also have been benefit in offering an additional validated instrument, such as The Spider, which is a symptom wheel designed for EDS/HSD (De Wandele et al, n.d.) which would offer an alternative format for recording symptoms.

Symptom Variability

The multisystemic nature of EDS/HSD, coupled with the broad spectrum of symptom prevalence, meant that even with the inclusion criteria of a formal diagnosis of EDS/HSD, the variability in participants' presentation was vast. On reflection, a more homogenous group should perhaps have been recruited. This could have been achieved firstly by limiting the Ehlers-Danlos criteria to hEDS only and by using the POQ scoring as one of the inclusion criteria. There was homogeny across gender in all three studies as all participants were female. This might be a consideration for the future researcher.

Whilst still a small-scale study of 10, the collaboration with Andrews and Ells helped expand the sample to 28 but of course this further broadened the variety of participants' presenting conditions. The variability of symptoms is referenced in the literature by Song et al. (2020) as problematic in suggesting one singular treatment approach which of course, within the confines of a study environment, is exactly what has to be achieved to create a measure. It is for that reason that we chose not to include any of the trigger point work that is recommended by Russek, Simmonds and Stott (2019), and is indeed one of the key components of the Jing Method™, as treating different muscles that seemed relevant for the individual, would of course create different treatments. Future studies could therefore consider choosing a particular problematic joint as part of the inclusion criteria to test this element.

It should be noted that all three studies (Andrews, Ells and Janneman) followed the same methodology though each had slightly different inclusion criteria around joint hypermobility/EDS /HSD. Andrews included adults scoring 6 or more on the Beighton Score of Hypermobility and Ells 5 or more. Both Andrews and Ells included diagnoses of hEDS only as opposed to the broader diagnoses of any of the Ehlers-Danlos Syndromes (in addition to HSD) that this study incorporated. In actuality, all except one participant of this study had a diagnosis of hEDS (they are diagnosed with Classical EDS), and so potentially being more specific in Ehlers-Danlos subtypes for future studies may be a useful consideration. With diagnostic criteria set to change in 2026, this will impact future studies regardless (The Ehlers-Danlos Society, 2025). These studies were also different entirely in design from Drew's (2024) four-person study which used a different methodology and validated instrument.

Variables beyond our control such as the weather, change in personal circumstances, injuries and illnesses occurred throughout this entire study period which certainly cannot be mitigated for but would have impacted the outcomes. Any measure of this is of course beyond the scope of this study.

Future

The findings of this and the combined studies could usefully be disseminated in conjunction with organisations such as The Ehlers-Danlos Society, EDS UK and The Hypermobility Syndromes Association. These charities also have funding available for research which may be a possibility to explore in developing further studies into massage for the EDS/HSD community. The Ehlers-Danlos Society hold global conferences with opportunities to present research, which would be worth exploring to communicate these findings and foster relationships for future collaboration. Approaching pilates and yoga studios, gyms and other movement professionals, to use these findings to educate staff about the importance of movement for people living with EDS/HSD could be an avenue to pursue to build relationships between massage and movement therapy. This is particularly timely as the imminent revision of diagnostic criteria and consequent drive to make diagnosis more accessible could lead to more people trying to access support.

CONCLUSION

The aim of this study was to investigate whether the Jing Method™ of Clinical Massage could improve the wellbeing of adults living with EDS/HSD. Despite its limitations it has quite clearly demonstrated that massage has a positive role to play in the lives of this community and within the broader context of healthcare.

As an extension of Jayne Drew's 2024 study and in collaboration with Andrews and Ells' parallel studies, it offers a roadmap for other therapists wishing to work with this population, in an area that is under-researched and under-documented. The review of the current literature, formulation of a treatment protocol and self-care offerings, plus the data itself, should provide a framework for therapists to proceed with confidence and safety in their work and offer reassurance to their clients.

This study demonstrates the active role that massage can play in the care of adults living with EDS/HSD, through the manual therapy itself but also the power of the therapeutic alliance and targeted aftercare. It dispels myths around the transient nature of massage through its Week 16 data, that measures the total impact of treatment as a mean average of 75.5 and which, with four weeks of no treatment, had only regressed slightly to the level at week 11 (75).

Whilst care for the EDS/HSD community still lacks NICE guidance, this study shows that advanced clinical massage therapists trained in the Jing Method™ have a key role to play in providing hope and a way forward for adults living with these conditions, which should not be underestimated.

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APPENDICES

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Appendix A

Jing BTEC Research Ethics Form

BTEC Level 6: Professional diploma in Advanced Clinical and Sports Massage

Section 1: to be completed by student

Student's name:	Jessica Janneman
Student number:	RC84156
BTEC Year-group:	2024-2026
Date of application:	08/05/2025
Student e-mail address:	jess_parfitt@yahoo.co.uk
Title of research project:	*Evaluating the effects of the Jing Method™ of Clinical Massage on the Wellbeing of adults diagnosed with Ehlers- Danlos Syndrome or Hypermobility Spectrum Disorder.*

Section 2: Does your project involve any primary research using human subjects?

Please indicate as appropriate.

	YES	**NO**
Does your project involve any primary research using human subjects?	**X**	
If yes, does it involve children under 16?		X
If yes, does it involve children under 18?		X
Other vulnerable populations (i.e. mental illness, aged subjects)?		x
Does your project involve NHS patients, NHS staff or Local Authority Service Providers?		X

Are you planning to use deception?		X
Are you collecting sensitive personal data such as sexuality, mental health data, etc.? *Only in relation to POQ*	X	
Does your study involve paying participants or an alternative incentive to participate		X
Could the study put you or someone else at risk of injury?		X
Does your project make use of a validated questionnaire?	X	
If yes, please specify the name of the validated questionnaire you are using and attach a copy here. Pain Outcomes Questionnaire (Short Form)		

Section 3: Research premises

Where is your research being undertaken? In my home clinic: Ease Therapies 6 Melton Road, Kings Heath, Birmingham, B14 7DA	
If your research is being undertaken outside of your own premises, do you have written confirmation from the establishment involved? If yes, please provide evidence.	Not applicable

Section 4: Recruitment

How will you recruit subjects for this research study?

-EDS UK West Midlands support group – paper fliers
-Facebook Groups: - EDS UK
  - Hypermobility Association
  - SEDS connective
  - General local pages: Kings Heathens/Moseley and Kings Heath/ B13/Everything Moseley/Jing Hub/The JAMMM
-My Instagram page
-Existing/Past client mailing list
-Local movement professionals: pilates/yoga/PT/circus/gymnastics/dance studios/ (by conversations and both soft and hard copies of the flier).
-WhatsApp groups of local networks: Kings Heath Running Club, School groups, Parents' Groups
-Fliers on local noticeboards

Section 5 Outline your project procedure

This is effectively a draft of your method, include information on when questionnaires will be used, what your intervention will involve, any stimuli used, etc.

This study will e*valuate the effects of the Jing Method™ of Clinical Massage on the Wellbeing of adults diagnosed with Ehlers- Danlos Syndrome or Hypermobility Spectrum Disorder.* Participants will be recruited via the methods above.

The advert distributed will display a QR code for all interested parties to click on. This will take them to a short questionnaire which will enable me to gain a little more information about them and check the inclusion/exclusion criteria.
Once they have expressed an interest and a group been selected, the Participant Letter will be distributed, following which, if they still wish to take part in the study, a 30 min 1-1 online call will be arranged to confirm suitability, explain the study, answer any questions, introduce the Pain Outcomes Questionnaire (POQ) and obtain consent.

-I will be using the Pain Outcomes Questionnaire (short form -20 questions) as my validated instrument.
-I will use a 'within subjects' design for my project, meaning my participants will act as their own control group.

Weeks 1-6: CONTROL PERIOD (no intervention)

POQ to complete every Monday with an email prompt. This is to obtain a baseline of their wellbeing, ahead of intervention.

Weeks 7-12: INTERVENTION PERIOD

-all 6 treatments are to be hands-on, in person treatments in my home treatment room.

Each weekly session will be 60 minutes in total and will consist of:
-a few minutes check-in on previous week, findings from self-care, feelings after treatment…
-a 45-minute hand-on treatment (Jing Method™ Chronic Stress & Pain Protocol (*Massage Fusion* pp. 355-369)) during which relaxing music will be played. The protocol will involve AMMA, heat, direct and indirect

myofascial release, effleurage, acupressure, PNF stretching and teaching. Each protocol will remain the same for each client and for each week

-a 10-minute self-care and breathwork routine for home use 3 times each week. This will be given in weeks 7, 9 and 11, some of which may be recorded and distributed to participants (this will be included as an appendix to the study).
Week 7 – a breathwork exercise
Week 9 – a new breathwork exercise plus an isometric exercise
Week 11 – a third breathwork exercise plus a proprioceptive exercise

POQ will be completed 6 days after each treatment (and within 24hours). At the same time the participant will be asked to inform the researcher how many times that week they have performed the self-care.

Week 16: Monday - POQ completed (with email prompt) to help assess longer-term benefits of treatment. Feedback sheet on study also distributed to help future studies.

Section 6: Describe what your participants need to do

Participants will be required to:

- complete the questionnaire via QR code on the study advert to help me determine suitability by asking questions to rule in participants with the inclusion criteria and out with the exclusion criteria.
- attend a 30 minute one-to-one online consultation, which will include completing my usual client intake form to help me gather medical and lifestyle information. Participants will also have an opportunity to ask any questions. During this meeting the participants will be required to sign the study consent form.
- inform me of any medical changes or new intervention/treatment that they undertake during the study period.

- Weeks 1 -6 complete the POQ weekly, on the Monday (they will be prompted by email)

- Weeks 7-12 attend their 60 minute in-person appointment at my clinic:

This will involve:
- a few minutes to check in on the previous week, raise any concerns, notify any changes to health/wellbeing etc.
-a 45 minute hands-on treatment which will follow the Jing Method ™ Chronic Stress and Pain Protocol which is a fusion of techniques such as AMMA, hot stones, effleurage, direct and indirect myofascial release, trigger point work, acupressure, stretching and the teaching of self-care.
-an introduction to that week's aftercare. Participants will be shown the exercises and will practice them to ensure they can perform them comfortably.

* 6 days after each treatment they will be required to complete the POQ (they will have 24 hours to complete this and be prompted by email) and inform me how many times they've completed their self-care.

- Weeks 7-12 complete their 10 minute self-care routine 3 times per week. This is constituted of:

Week 7 – breathwork exercise

Week 9 – a new breathwork exercise plus an isometric exercise

Week 11 – a third breathwork exercise plus a proprioceptive exercise

- Week 16 complete a final POQ and feedback sheet for future study.

Section 7: Respecting confidentiality and ethical issues for participants

How will you manage participant confidentiality? Ensure that the information refers to GDPR and is compliant with this legislation. What ethical considerations are there?

CONFIDENTIALITY

All data will be held in accordance with GDPR. Data is stored on the researcher's password protected laptop which is only accessed by her. All data held in regard to this study will be destroyed following its completion. Participant data will be anonymized using a numeral system.

ETHICAL ISSUES

Own bias. I have EDS as does my daughter. I need to be careful not to allow this to influence my feelings towards the project or towards my clients and be conscious of how much I share.

Mental Health/Trauma. Participants may have had a history of mental illness and trauma (including medical) which is something to be aware of and sign-post appropriately. I will use my training to keep the participant safe and green-cross code where necessary.

Consent and Withdrawal Consent will be gained from every participant and they will be made fully aware of all that is involved in the study (by letter and consultation). They will be made aware that they can choose to withdraw from the study at any time.

Injury/Risk I am a fully-insured and trained therapist and have a First Aid kit accessible. All self-care movements will be taught and observed. The participants will be advised to keep all movements within a pain-free range and stop if they are causing pain. I will be mindful of raising clients legs to help PoTs symptoms if appropriate.

Section 8: Inclusion and exclusion criteria

What sort of people will the subjects be?

The study will include:
-Adults (people over the age of 18) with a diagnosis of either Ehlers-Danlos Syndrome or Hypermobility Spectrum Disorder from a medical professional.
The study will exclude:
-anyone who is pregnant

-anyone who has had surgery within the last 8 months -anyone who has a health condition that is unrelated to EDS/HSD (cancer for example).

Section 9: Student declaration:

I understand that I can only start my project, once this ethical application has been approved. This applies to ALL projects, whether using human participants or not.	YES	

Student's handwritten signature:

____

(To be completed, once ethical approval has been provided)

Print Name: **Jessica Janneman** **Date:** **08/05/2025**

ONCE YOU HAVE COMPLETED THE ABOVE ETHICS DETAILS, THEN YOU CAN PROCEED TO PARTICIPANT INFORMATION AND CONSENT FORMS, SO READ BELOW AS IT IS IMPORTANT TO BE CLEAR ABOUT WHAT YOUR PARTICIPANTS NEED TO DO.

Informed consent must be obtained for **all** participants before they take part in your project. The Consent Form should clearly state the parameters and content of the research. It should explain what is expected of the participants and what they will be doing. It should draw specific attention to any elements that could conceivably cause subsequent objections, and the measures you are taking to ensure the confidentiality of their data. It should also state that the participants are free to withdraw from the study at any time.

Studies should not involve participants under 18 without express permission from your supervisor. Studies carried out in schools require the permission of the head-teacher, and of any responsible adults as per the head teachers' recommendation. Minors aged over 14 years should also sign an individual consent form themselves. If you are planning to carry out a project whereby you will be in contact with minors, you must establish from the head-teacher or other responsible adult whether the work proposed will require you to have the relevant DBS disclosure. Please seek advice from your Local Authority.

You must complete a consent form for every participant involved in your study.
Jing's assessment (to be signed by Jing after ethics and participant information details completed)

EITHER:
This project is not designed to include fieldwork with human participants. Insofar as secondary data are to be used, I am confident that appropriate procedures are in place for data protection and non-disclosure of any personal or confidential data.

Signature: ....date: ....

OR:
This project is designed to include fieldwork with human participants.
(please circle yes or no)

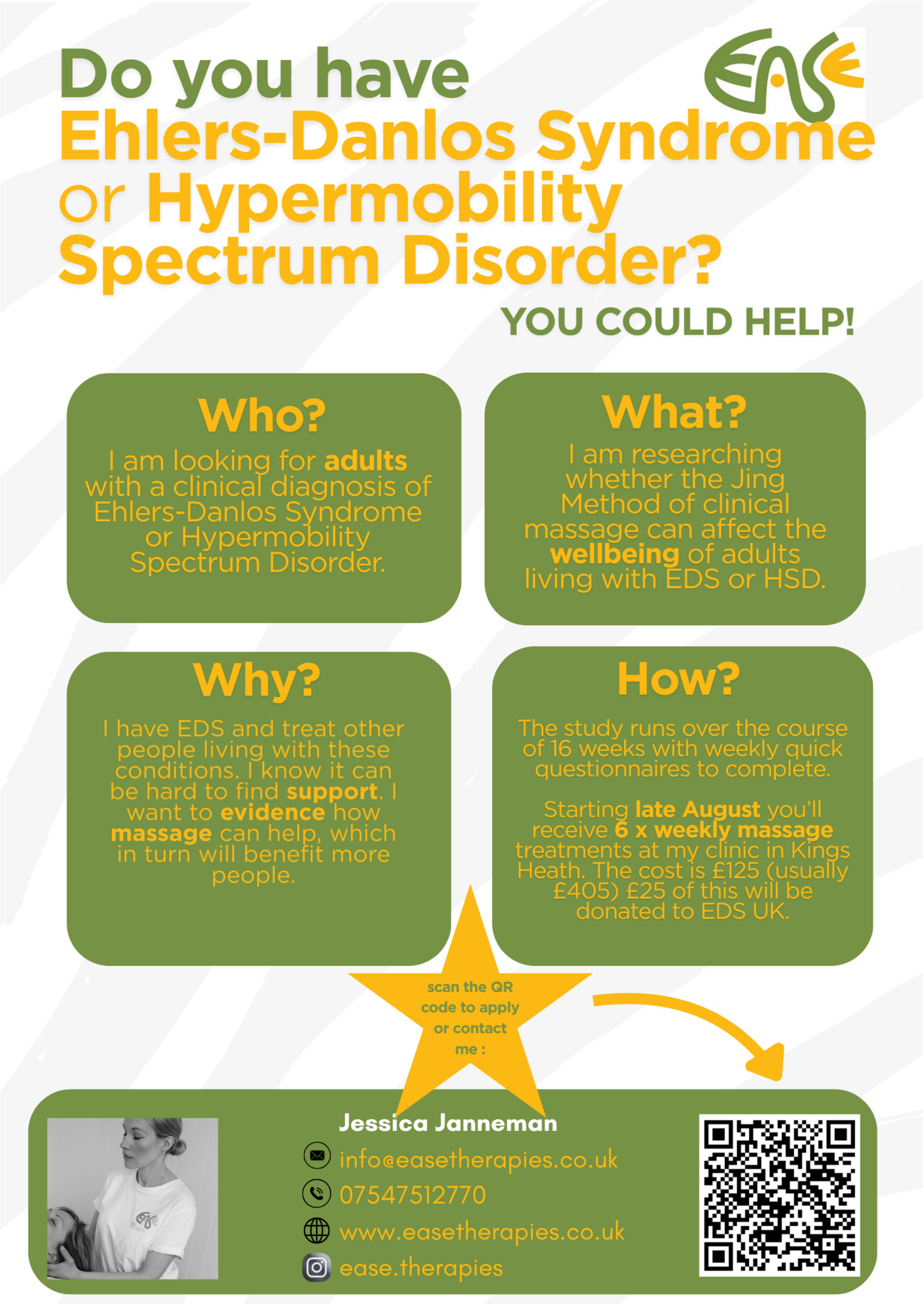
YES	All necessary statutory, legislative or other formal external approvals have been obtained (e.g., permissions, police checks, external research ethics and governance approvals in the case of research involving NHS staff or patients or Local Authority service providers or users).
YES	The design of this study ensures that the dignity, welfare and safety of the participants will be ensured and that if children or other vulnerable individuals are involved they will be afforded the necessary protection.
YES	I am confident that participants will be given all necessary information before the study, in the consent form, and after the study if necessary.
YES	I am confident the participants' confidentiality will be preserved.
YES	I consider that any risks involved to the student, the participants, and any third party are minimal.
YES	I consider that Departmental approval should be given, since ethical risks have been appropriately addressed in the proposal and I am confident that steps will be taken to minimise any risks.

Signature: ....Susan Harrison................................. date: ....12/5/25............

If a second opinion was sought from a research ethics expert, the advisor should also sign this form below:
Advisor's name (please print):

Advisor's signature: .... date: ....
Once the Jing's signature has been obtained, the student must return the completed form to the Jing Office.

Appendix B



Do you have **Ehlers-Danlos Syndrome** or **Hypermobility Spectrum Disorder?**

YOU COULD HELP!

Who?

I am looking for **adults** with a clinical diagnosis of Ehlers-Danlos Syndrome or Hypermobility Spectrum Disorder.

What?

I am researching whether the Jing Method of clinical massage can affect the **wellbeing** of adults living with EDS or HSD.

Why?

I have EDS and treat other people living with these conditions. I know it can be hard to find **support**. I want to **evidence** how **massage** can help, which in turn will benefit more people.

How?

The study runs over the course of 16 weeks with weekly quick questionnaires to complete.

Starting **late August** you'll receive **6 x weekly massage** treatments at my clinic in Kings Heath. The cost is £125 (usually £405) £25 of this will be donated to EDS UK.

scan the QR code to apply or contact me :

Jessica Janneman

✉ info@easetherapies.co.uk

☎ 07547512770

🌐 www.easetherapies.co.uk

📷 ease.therapies

Appendix C

EASE
MUSCULOSKELETAL
PAIN THERAPIES

Ease Therapies
6 Melton Road
Kings Heath
Birmingham B14 7DA
info@easetherapies.co.uk
www.easetherapies.co.uk

07547512770

Jing Institute of Massage and Complementary Medicine
28/29 Bond Street
Brighton BN1 1RD

www.jingmassage.com

01273 628942

Dear

Re: Research Study

Thank you for showing interest in my study. I really appreciate you responding to my call for participants. I'd like to tell you a little more about what it entails.

I have been a massage therapist since 2020 and I specialise in the treatment of chronic pain. In my clinic, I work mostly with individuals suffering with a range of complex persistent pain conditions such as Ehlers-Danlos Syndrome and Hypermobility Spectrum Disorder.

In 2022, I embarked on an advanced degree level qualification in my field: the BTEC Level 6 in Advanced Clinical and Sports Massage. This is offered by the Jing Institute of Advanced Massage Training, which has been an industry leader for the past 22 years. It is the highest level of education a massage therapist can achieve in the UK and is overseen by experts in the field of Musculoskeletal Pain, Education, Sports Science and Psychology.

As the final part of our course, we are given an opportunity to design and carry out a study into the efficacy of a clinical massage programme. I have chosen to investigate the effects of the Jing Method of clinical massage on the wellbeing of people diagnosed with EDS or HSD.

I am looking for people:

- Who are over 18 years old
- Have been diagnosed with either Ehlers-Danlos Syndrome (EDS) or Hypermobility Spectrum Disorder (HSD)

If you decide to participate in the study, it will start the week beginning July 13th 2025. Participation is completely voluntary and you can withdraw from the study at any time without giving a reason. All your information will be kept confidential and your data will be anonymised.

What does the study involve?

We will have an initial 30 minute 1-to-1 online meeting where we talk through the study and confirm your suitability. I will gather your contact info, and introduce you to the Pain Outcomes Questionnaire, which I will be asking you to complete during the study. Once the study is fully explained to you, you can give your consent to take part.

The first 6 weeks (13th July – 24th August) is about understanding your wellbeing. During this time, every Monday, you will fill in the questionnaire. It is made up of 20 questions and so should take you no more than 5 minutes to complete. I will send you an email prompt to remind you. Once all this data is gathered, we will then move onto the hands-on, in person phase.

For weeks 7-12 (24th August – 5th October) you will receive one 45 minute clinical massage treatment per week at my clinic in Kings Heath. I will also teach you a short routine of self-care exercises to perform 3 times per week at home. Each session will be an hour in total.

During these 6 weeks, you will continue to fill out the Pain Outcomes Questionnaire, 6 days after treatment. I will continue to send you an email prompt and will ask how many times you have performed the self-care routine.

Four weeks (3rd Nov) after the last hands-on treatment you will fill out the Pain Outcomes Questionnaire for the final time. At this time, I will also ask you to complete some feedback to help any further research. This should only take you around 5 minutes.

Are there any risks or benefits to taking part?

There is a small risk that you may feel some expected muscle soreness from completing the self-care exercises. Hopefully your overall experience will be that of a greater sense of wellbeing.

What will happen to my data?

Your data will be mathematically analysed together with all the other participants' data, and the findings from this analysis will be communicated to the project supervisor and possibly other practitioners. All your information will be anonymised.

Once my research is published, I will share with you my findings and invite you to a conference, where my colleagues and I will be presenting our studies.

It is very important that you don't engage in another other new pain-relieving activity including the use of pain medication or trying a new therapy for your wellbeing without letting me know.

Cost

Such treatments with myself are usually priced at £65 per hour.

I will be offering all 6 treatments for this study as a package of £125 which can be paid in its entirely at the start of the study or in 2 instalments at Weeks 1 and 7.

£25 of each package will be donated to EDS uk.

Please do get in touch with any questions that you may have.

Thank you again for considering this project. I truly believe your participation will make a difference to your wellbeing and that of others living with EDS/HSD.

With Very Best Wishes,

Jessica Janneman ACMT.

PARTICIPANT CONSENT FORM

Title of study: Evaluating the effects of the Jing method™ of clinical massage on the wellbeing of adults with a diagnosis of Ehlers-Danlos Syndrome or Hypermobility Spectrum Disorder.

Name of student: Jessica Janneman

	Yes	No
I have read the information letter about this study		
I have had an opportunity to ask questions and discuss this study		
I have received satisfactory answers to all my questions		
I have received sufficient information about this study		
I understand that I am free to withdraw from this study: • At any time (until such date as this will no longer be possible, which is once all anonymised data has been merged) • Without giving a reason for withdrawing • That I am free to refuse to answer any question without saying why		
I understand that the Zoom consultation will not be recorded.		
I agree to take part in this study		
Signature (participant) **Date:**		
Name: (BLOCK LETTERS)		
BTEC students contact details (including telephone number and e-mail address): **Jessica Janneman** **Tel no: 07547512770** **Email:** info@easetherapies.co.uk		

Appendix D

PAIN OUTCOMES QUESTIONNAIRE (Short form)

MichaelE.Clark,Ph.D.andRonaldJ.Gironda,Ph.D.

JamesA.HaleyVeteransAffairsHospital,Tampa,Florida.

We ask that **all patients regardless of condition** complete the remainder of the questionnaire.

I. INSTRUCTIONS:

Please circle the number that best describes the question being asked.
Choose only 1 number per question.

1) Enter today's date: _____/_____/________ (dd/mm/yyyy)

2) On a scale of 0 to 10, with 0 being no pain at all and 10 being the worst possible pain, how would you rate your pain on average during the **past week**?

← →
No Pain 0 1 2 3 4 5 6 7 8 9 10 **Worst Possible Pain**

3) Does your pain interfere with your ability to walk?

← →
Not at all 0 1 2 3 4 5 6 7 8 9 10 **All the time**

4) Does your pain interfere with your ability to carry/handle everyday objects such as a bag of groceries or books?

← →
Not at all 0 1 2 3 4 5 6 7 8 9 10 **All the time**

5) Does your pain interfere with your ability to climb stairs?

← →
Not at all 0 1 2 3 4 5 6 7 8 9 10 **All the time**

6) Does your pain require you to use a cane, walker, wheelchair, or other devices?

← →
Not at all 0 1 2 3 4 5 6 7 8 9 10 **All the time**

7) Does your pain interfere with your ability to bathe yourself?

← →
Not at all 0 1 2 3 4 5 6 7 8 9 10 **All the time**

8) Does your pain interfere with your ability to dress yourself?

← →
Not at all 0 1 2 3 4 5 6 7 8 9 10 **All the time**

9) Does your pain interfere with your ability to use the bathroom?

← →

Not at all 0 1 2 3 4 5 6 7 8 9 10 **All the time**

10) Does your pain interfere with your ability to manage your personal grooming (for example, combing your hair, brushing your teeth, etc.)?

← →

Not at all 0 1 2 3 4 5 6 7 8 9 10 **All the time**

11) Does your pain affect your self-esteem or self-worth?

← →

Not at all 0 1 2 3 4 5 6 7 8 9 10 **All the time**

12) How would you rate your physical activity?

← →

Significant limitation in basic activities 0 1 2 3 4 5 6 7 8 9 10 **Can perform vigorous activities without limitation**

13) How would you rate your overall energy?

← →

Totally worn out 0 1 2 3 4 5 6 7 8 9 10 **Most energy ever**

14) How would you rate your strength and endurance **today?**

← →

Very poor 0 1 2 3 4 5 6 7 8 9 10 **Very high**

15) How would you rate your feelings of depression **today?**

← →

Not at all depressed 0 1 2 3 4 5 6 7 8 9 10 **Extremely depressed**

16) How would you rate your feelings of anxiety **today?**

← →

Not at all anxious 0 1 2 3 4 5 6 7 8 9 10 **Extremely anxious**

17) How much do you worry about re-injuring yourself if you are more active?

← →

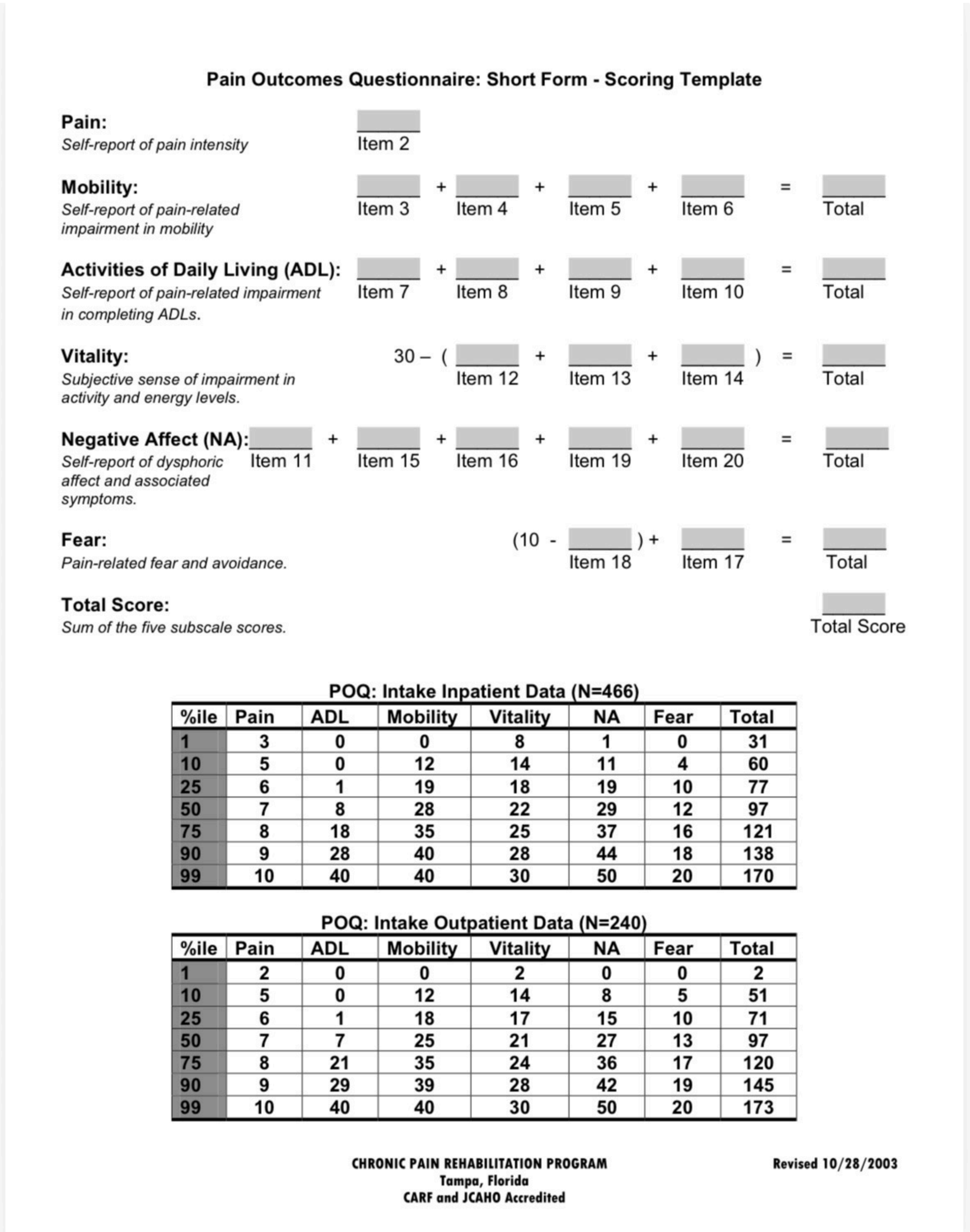
Not at all 0 1 2 3 4 5 6 7 8 9 10 **All the time**

18) How safe do you think it is for you to exercise?

← →

20) How often do you feel tense?

←											→
Not at all	0	1	2	3	4	5	6	7	8	9	10 **All the time**



Pain Outcomes Questionnaire: Short Form - Scoring Template

Pain:
Self-report of pain intensity
____ Item 2

Mobility:
Self-report of pain-related impairment in mobility
____ Item 3 + ____ Item 4 + ____ Item 5 + ____ Item 6 = ____ Total

Activities of Daily Living (ADL):
Self-report of pain-related impairment in completing ADLs.
____ Item 7 + ____ Item 8 + ____ Item 9 + ____ Item 10 = ____ Total

Vitality:
Subjective sense of impairment in activity and energy levels.
30 – (____ Item 12 + ____ Item 13 + ____ Item 14) = ____ Total

Negative Affect (NA):
Self-report of dysphoric affect and associated symptoms.
____ Item 11 + ____ Item 15 + ____ Item 16 + ____ Item 19 + ____ Item 20 = ____ Total

Fear:
Pain-related fear and avoidance.
(10 - ____ Item 18) + ____ Item 17 = ____ Total

Total Score:
Sum of the five subscale scores.
____ Total Score

POQ: Intake Inpatient Data (N=466)

%ile	Pain	ADL	Mobility	Vitality	NA	Fear	Total
1	3	0	0	8	1	0	31
10	5	0	12	14	11	4	60
25	6	1	19	18	19	10	77
50	7	8	28	22	29	12	97
75	8	18	35	25	37	16	121
90	9	28	40	28	44	18	138
99	10	40	40	30	50	20	170

POQ: Intake Outpatient Data (N=240)

%ile	Pain	ADL	Mobility	Vitality	NA	Fear	Total
1	2	0	0	2	0	0	2
10	5	0	12	14	8	5	51
25	6	1	18	17	15	10	71
50	7	7	25	21	27	13	97
75	8	21	35	24	36	17	120
90	9	29	39	28	42	19	145
99	10	40	40	30	50	20	173

CHRONIC PAIN REHABILITATION PROGRAM
Tampa, Florida
CARF and JCAHO Accredited

Revised 10/28/2003

Appendix E

Treatment Protocol

(adapted Jing Method™ Stress and Chronic Pain Protocol – Massage Fusion pp.355-369)

Prone over drape

- Grounding - hands on sacrum and scapula
- Deep grounding/relaxation - forearms either side of spine, sinking in, shifting weight
- Double palm erectors
- Back shu points (bladder channel)

Prone (no drape)

- MFR - cross hand stretch to upper trapezius
- Lean in with forearms at upper trapezius
- MFR - cross hand stretch - sacrum and lumbar spine
- Lean in with forearms at lumbar area
- Single forearm effleurage to lumbar area from side of table x 3
- Power effleurage with hot stones x 3
- Deep forearm work to erectors from head of table x 3
- Tune in with hands on sacrum and shoulder blades

Supine

- Place hot stones on solar plexus and belly
- Hands on stones and tune in
- MFR pelvic transverse plane release (belly sandwich)
- MFR solar plexus transverse fascial plane release
- MFR fascial single leg pulls
- Bent knee hamstring PNF stretch – each side
- Ki 1 (Gushing Spring)
- Conception vessel
- Diaphragm – static compressions
- Strip intercostals – upper and lower ribs
- Deep work to posterior neck – distal to proximal
- CV 17 (Chest Centre)
- Shampooing head
- Pressure points across forehead
- Massage around jaw – medial to lateral
- GV 20 (Hundred Convergences)
- Still head hold

Appendix F

Self-Care

Each set of self-care exercises to take no longer than 10 minutes and performed 3 times per week.

Weeks 7 and 8

- Relaxation and breathwork, introducing lengthening of the exhale to activate parasympathetic nervous system. An audio recording was sent to client in week 7 following an introduction in their session, a summary of which is below.

    - Finding a comfortable position without any distractions, ideally lying supine with knees bent or a cushion/pillow under the knees, but if that is uncomfortable, lying on your side or sitting comfortably. Close your eyes if that feels good.
    - Bring your awareness to your breathing, noticing that you're breathing in and breathing out and how you know that you're breathing in and breathing out. Observe the breath moving in and out of your body.
    - Bring your awareness to your exhale. Every time you exhale allow your body to soften/melt/let go/surrender (whatever word resonates with you) into whatever you're lying on, to the extent that you can, with no judgement. Allow gravity to really do its job on you, so your bones naturally become heavier every time you breathe out.
    - Coming back to your inhale and your exhale for a moment. Breathe a little more slowly and a little more deeply. Without forcing anything, allow your exhale to become a little longer than your inhale. Again, no judgement with this, just allowing your exhale to lengthen a little. Continue for 2 minutes. Then wiggle your fingers and toes, open your eyes and bring your awareness back into the room.

- Self-treatment of acupressure point LI 4 (Union Valley/Great Eliminator) – 3 times per day (on the 3 days that self care is performed), holding for 12 seconds on each hand. Participants to choose when to do this.

Weeks 9 and 10

- Relaxation and Resonance Frequency breathing (5 minutes) to activate parasympathetic nervous system. An audio recording was sent to client in week 9 following an introduction in their session, a summary of which is below.

    - Finding a comfortable position without any distractions, ideally lying supine with knees bent or a cushion/pillow under the knees, but if that is uncomfortable, lying on your side or sitting comfortably. Close your eyes if that feels good.
    - Bring your awareness to your breathing, noticing that you're breathing in and breathing out and how you know that you're breathing in and breathing out. Observe the breath moving in and out of your body.
    - Bring your awareness to your exhale. Every time you exhale allow your body to soften/melt/let go/surrender (whatever word resonates with you) into whatever you're lying on, to the extent that you can, with no judgement. Allow gravity to really do its job on you, so your bones naturally become heavier every time you breathe out.
    - Coming back to your inhale and your exhale. Breathe a little more slowly and a little more deeply, allowing your exhale to become a little longer than your inhale. Start counting the length of your inhale and the length of your exhale. Again, no judgement with this. Ultimately we are aiming for an inhale of 4 and an exhale of 6, but 2/4 or 3/5 (or somewhere in between) is fine. Continue for 5 minutes. Then wiggle your fingers and toes, open your eyes and bring your awareness back into the room.

- Self-treatment of acupressure point LI 4 (Union Valley/Great Eliminator) – 3 times per day (on the 3 days that self care is performed), holding for 12 seconds on each hand. Participants to choose when to do this.

- Pelvic tilts – 8 repetitions

    - Lie supine with knees bent, arms by your side and feet flat on the floor hip distance apart

    - Inhale to prepare
    - Exhale and tuck your pelvis, rounding your low back towards the floor as if you were rolling a marble on your lower belly up towards your belly button
    - Inhale and tilt your pelvis, rolling the marble down towards your pubic bone
    - If you feel any discomfort, reduce the range of movement, making the tuck and the tilt much smaller

Weeks 11 and 12

- Relaxation and Resonance Frequency breathing (7 minutes) to activate parasympathetic nervous system. An audio recording was sent to client in week 11 following an introduction in their session, a summary of which is below.

    - Finding a comfortable position without any distractions, ideally lying supine with knees bent or a cushion/pillow under the knees, but if that is uncomfortable, lying on your side or sitting comfortably. Close your eyes if that feels good.
    - Bring your awareness to your breathing, noticing that you're breathing in and breathing out and how you know that you're breathing in and breathing out. Observe the breath moving in and out of your body.
    - Bring your awareness to your exhale. Every time you exhale allow your body to soften/melt/let go/surrender (whatever word resonates with you) into whatever you're lying on, to the extent that you can, with no judgement. Allow gravity to really do its job on you, so your bones naturally become heavier every time you breathe out. You might notice that your body is able to relax more quickly now you’ve been practicing this for a few weeks.
    - Coming back to your inhale and your exhale. Breathe a little more slowly and a little more deeply, allowing your exhale to become a little longer than your inhale. Start counting the length of your inhale and the length of your exhale. Again, no judgement with this. Ultimately we are aiming for an inhale of 4 and an exhale of 6, but as before 2/4 or 3/5 is fine (notice if this has changed at all or become easier

with your practice). Continue for 7 minutes. Then wiggle your fingers and toes, open your eyes and bring your awareness back into the room.

- Self-treatment of acupressure point LI 4 (Union Valley/Great Eliminator) – 3 times per day (on the 3 days that self care is performed), holding for 12 seconds on each hand. Participants to choose when to do this.

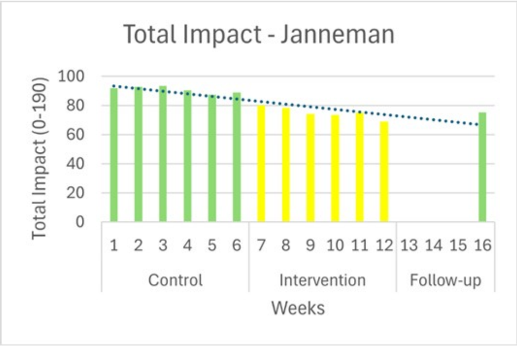
- Pelvic clock – 8 repetitions in each direction
    - Lie supine with knees bent, arms by your side and feet flat on the floor hip distance apart.
    - Imagine there is a clock on the back of your pelvis with 12 o'clock at the top of your sacrum, 6 o'clock at your tailbone and 3 and 9 o'clock at your hips.
    - Roll the marble back towards 12 o'clock and then roll it around all the numbers on the clock (from 1 to 2 to 3 etc) until it comes back to 12, noticing whether any of the numbers feel sticky or stiff. Repeat 7 times seeing if you can smooth the circles out as you go. Keep breathing throughout (make sure you aren't holding your breath) and don't force anything.
    - Repeat in the other direction (from 11 to 10 to 9 etc)
    - If you feel any discomfort, reduce the range of movement or return to pelvic tilts.

Appendix G

RESULTS TABLE AND GRAPHS

POQ score percentage reductions for this (Janneman) and combined (Andrews, Ells and Janneman) studies.

Category	This Study (% reduction)		Combined Studies (% reduction)	
	Week 12	**Week 16**	**Week 12**	**Week 16**
Total impact	25.1	18	23.0	20.0
Pain intensity	33.3	24	32.7	17.2
Pain related impairment of mobility	24.1	18	32.9	27.5
Pain related impairment in completing activities of daily living	20	11.3	34.8	31.6
Vitality – impairment in activity and energy levels	21.9	21	10.5	12.7
Negative effect – dysphoric affect and associated symptoms	31.5	18.1	22.1	20.3
Pain-related fear and avoidance	21.7	14	19.3	15.1


Total Impact - Janneman
Total Impact (0-190)
100
80
60
40
20
0
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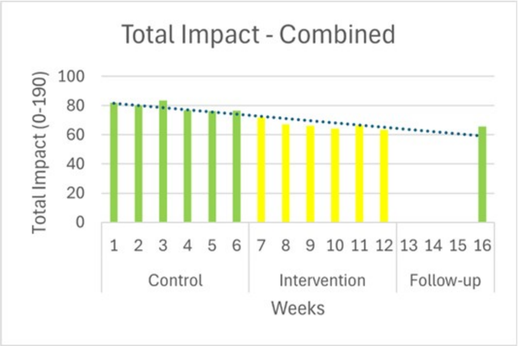
Control
Intervention
Follow-up
Weeks


Total Impact - Combined
Total Impact (0-190)
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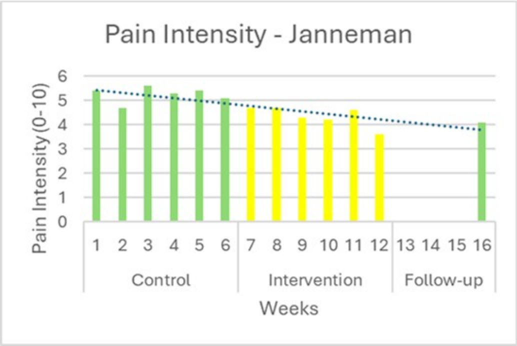
80
60
40
20
0
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Control
Intervention
Follow-up
Weeks


Pain Intensity - Janneman
Pain Intensity (0-10)
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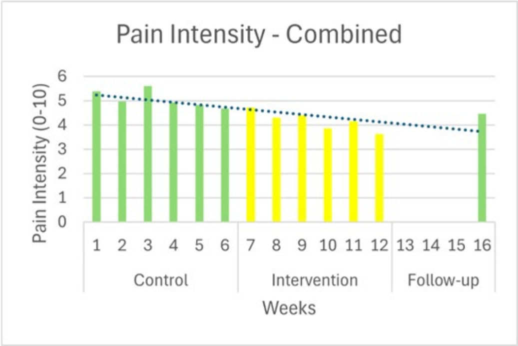
5
4
3
2
1
0
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Control
Intervention
Follow-up
Weeks


Pain Intensity - Combined
Pain Intensity (0-10)
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5
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2
1
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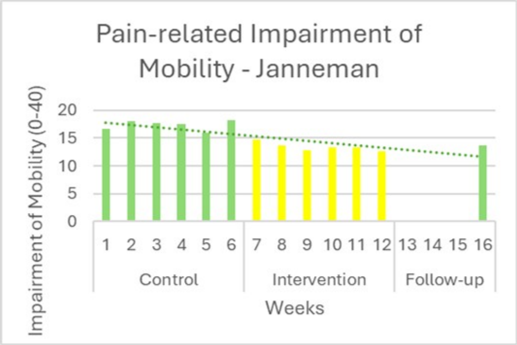
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Control
Intervention
Follow-up
Weeks


Pain-related Impairment of Mobility - Janneman
Impairment of Mobility (0-40)
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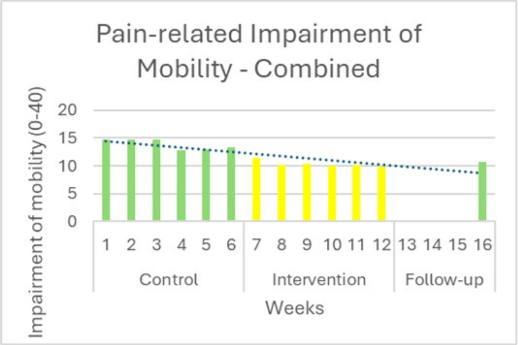
15
10
5
0
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Control
Intervention
Follow-up
Weeks


Pain-related Impairment of Mobility - Combined
Impairment of mobility (0-40)
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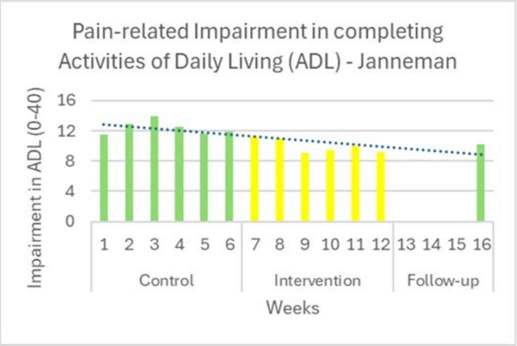
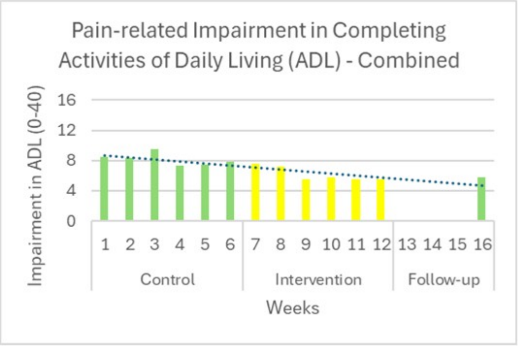
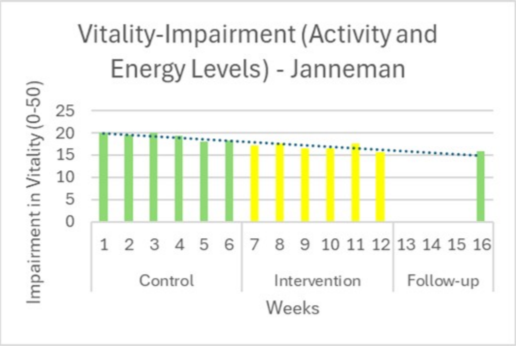
15
10
5
0
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Control
Intervention
Follow-up
Weeks


Pain-related Impairment in completing Activities of Daily Living (ADL) - Janneman
Impairment in ADL (0-40)
16
12
8
4
0
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Control
Intervention
Follow-up
Weeks


Pain-related Impairment in Completing Activities of Daily Living (ADL) - Combined
Impairment in ADL (0-40)
16
12
8
4
0
1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16
Control
Intervention
Follow-up
Weeks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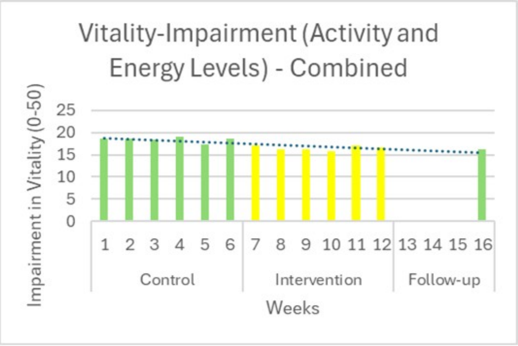
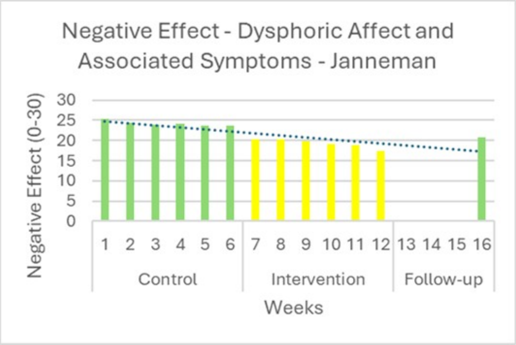
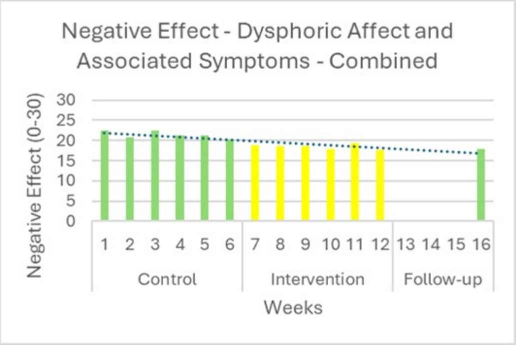
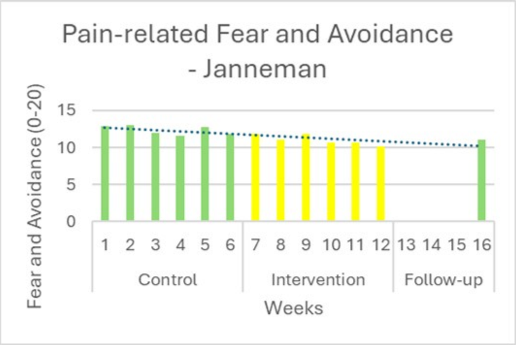
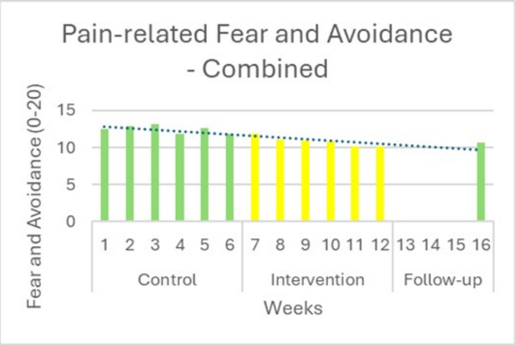

Vitality-Impairment (Activity and Energy Levels) - Combined


Negative Effect - Dysphoric Affect and Associated Symptoms - Janneman


Negative Effect - Dysphoric Affect and Associated Symptoms - Combined


Pain-related Fear and Avoidance - Janneman


Pain-related Fear and Avoidance - Combined

Appendix H

Feedback Form

Thank you so much for taking the time to complete this form. Please answer as fully as you would like.

All informative given will be anonymised and may be included in the study findings as well as informing future research.

1. Why did you choose to take part in this study?
2. What did you find beneficial in the study?
3. How did you find the self-care element? Have you continued with any of this following the last hands-on treatment?
4. From this experience, in what way/s do you think clinical massage could play a role for people living with HSD/EDS, if at all?
5. What have you gained/learned by taking part in this study?
6. Do you have any suggestions for improving this study in the future?
7. This is an opportunity to provide any general feedback (eg. the running and design of the study itself, the symptom management it may offer, where it fits as part of HSD/EDS care more generally…)

Appendix I

Week 16 FEEDBACK FORM RESPONSES

Participants are numbered for anonymity.

(Participant 10 didn't return their form)

Q1. Why did you choose to take part in this study?

1.To see if regular therapeutic massage could reduce the issues related to being hypermobile

2. I have EDS and experience a number of daily difficulties as a result. I was delighted to hear someone is doing a study into potential non-pharmacological ways to reduce or manage some of these symptoms.

3. I chose to take part in the study because I am looking for ways to reduce my pain so that I can use movement to restore my function and ultimately to build strength.

4. I have flare ups with my hypermobility and wanted to do something to support my health. I also wanted to contribute to something that was focusing on these conditions, which often take a long time to diagnose and aren't always considered as difficult

5. To see if a new treatment would help my eds

6. I chose to take part in the study primarily because finding practitioners who have any knowledge of EDS, let alone are able to offer any support for the condition, are few and very far between. I was delighted to discover that the study was being conducted, even more so that it was being held nearby to where I live. I also took part because I'm always eager to learn more about my condition, and also to help others through my particpation in the process - both other EDS patients, as well as practitioners who wish to support them.

7. Due to the limited information or knowledge known when i encounter medical professional physical rehabiltation etc i believe it could provide a base of information and get the condition explored and acknowledged . I was keen to familiarise myself with the jing method at a particualrly stressful period of time .

8. To find alternative ways to manage pain, and to help explore new things that might help others too.

9. To find new ways to manage pain associated with eds

Q2. What did you find beneficial in the study?

1.Having time for me. Being given permission to relax. Having a kind person to relate to

2. It was hugely validating to feel seen and understood in the struggles I face. I was well-looked after and cared for and felt calmer and more at ease in my body thanks to the massage treatment. I had a number of extremely stressful things going on in life alongside the study and also had sustained some injuries in the summer just before which probably impacted the overall effects and which was unfortunate, but even saying that, I found the time during and couple of days after massages did relieve my overall pain levels (not connected with the specific injuries), as well as my anxiety levels over those weeks.

3. The direct work with Jess was incredibly beneficial and really suprised me. I have tried so many different forms of alternative therapy that have all flared up my pain and set me back. This is the first time I found something that not only reduced my pain but allowed me to begin movement again.

4. The hands on treatment, and monitoring my own health more closely

5. Weekly time for relaxation both mentally and physically which helped me throughout the week too

6. I found SO much that was beneficial in the study - first and foremost, having the opportunity to meet and talk with another person with EDS - this is incredibly rare, and having that connection has validated so much of what I have had to face alone. To know that I'm not alone, that my symptoms and setbacks are normal for someone else too, has been a rare gift. As well as that side, I found the massage treatment itself to be incredbily soothing, and beneficial in helping me connect even more with my body, how it feels, and my relationship to pain. I found the self-care element beneficial also - though I have already regularly practiced similar exercises in my day-to-day life, they served as a great reminder of just how important self care is, and that one's healing, and relationship to pain, begins within.

I also found the chats before and after treatments super helpful - having the opportunity to reflect on what I had experienced since the last treatment, as well as what I had experienced in the session itself, was incredibly insightful and helped me bridge the gap between merely receiving a treatment, and being able to truly understand the mechanics of it all.

7. relaxation , interacting with Jessica about the breathing techniques and ways my diagnosis has impacted my health , and shared knowledge about how the type of breathe may help with anxiety reduction and health benefits

8. The treatment helped me sleep better, which ultimately allowed me to manage my pain better. Another thing I found was that even when I hadn't slept as well, or was feeling overwhelmed, I felt like I was able to tolerate it slightly better. My hands, even though they weren't treated directly, have been in less pain since the treatment.

9. Regular appointments and check-ins

Q3. How did you find the self-care element? Have you continued with any of this following the last hands-on treatment?

1.I found it v hard to add in as another thing into my hectic life. But when I did it it was definitely therapeutic. I have carried on the tummy exercises and I hope I can Include the relaxing exercises as needed

2.The self-care is something I am variable with mostly due to my mental and emotional state: when I have done this it has been very beneficial, soothing and even strengthening, but in recent weeks because of everything else going on in life I have struggled to be motivated to carry out the exercises consistently, which is completely on me.

3. The self care elements were helpful because they weren't difficult it and helped me to begin a base line of movement and breath work that kickstarted a routine of sorts.

4. I found it a bit difficult to relax with the breathing exercises but they did help me to take time out to focus on releasing the stress

5. Difficult to concentrate on breathing but I got better at it as time went on. The physical movements were easy to do. I do the pelvic clock every so often and try to slow my breathing to relax too

6. I love the self care element. As above, many of the exercises were already part of my daily practice, so it was easy for me to incorporate the self care element into my existing routine. I especially enjoyed learning a few new techniques, such as the pelvic floor rotation, and I have continued several of the techniques by bringing them into my daily routine.

I can definitely see the value in including the self care elements for those who may not already have an established self care routine, as I believe it to be a fundamental part of the ongoing work.

7. Yes the selfcare , made me observe how little time i spent relaxing and trying to realign my body joints , which daily i experience as out of line and and painful . Simply making the time to lie upon the floor and breathe and try to use the saml breath movement , acupressure point generally does help me feel better . Breathing deeply in to the ribcage is now a daily occurance if only for few minutes .

8. I found the self-care element very helpful. I found the breathing exercises helpful with managing my pots symptoms in particular (especially adrenaline dumps). I have continued with this and the hip tilts, as I'm finding it helpful to try and work on my proprioception. I found it difficult at times to remember to do the treatment because of my adhd but really appreciated the reminders and felt that there was a good amount of exercises to follow. I appreciated the email reminders with instructions as especially straight after treatment my brain sometimes struggled to take verbal instructions on.

9. Some elements I found easier than others such as the physical tasks. Which I did find helpful. I have always struggled with doing breathing meditation activities, i did try them but found them difficult.

Q4. From this experience, in what way/s do you think clinical massage could play a role for people living with HSD/EDS, if at all?

1.Relaxing, helping both mental and physical state

2. I think the particular reduction in joint and muscle pain is excellent and on its own very much means massage should be considered a highly valuable and integral part of a treatment plan for those with EDS/HSD. The fact it also helps in reducing anxiety levels is a bonus, but not one to be overlooked as anxiety and levels of low mood are definitely higher in this population due to the day-to-day difficulties presented by these conditions.

3. I think it's a really vital role. For me, whenever I tried to begin movement again (and I have been trying this for years with physio's, one that I ended up working with 4 times a week to try and create consistency) I ended up in a flare, my muscles would spasms and it would take weeks to recover. No amount of meditation and breathwork alone was helping me get beyond this flaring. When I worked with Jess, I was suprised to find that I could move beyond this flaring and begin to build a routine of movement exercises.

4. I found myself really relaxed afterwards and for the few days after I felt like I was less tense (which helps my joints not seize) and more productive.

5. Time dedicated to relaxing, it helps to calm the nervous system and relax my muscles a bit

6. More than anything, AWARENESS. Not of the condition per se, but awareness of patients own feelings within their own bodies. The ability to be able to tune into the body and listen to, and respond to, what it tells us. The crucial, often overlooked, aspect of being SEEN by someone who understands the condition, and knows how to best treat it, opposed to mainstream techniques that can often do more harm than good.

7. The jing method is suitable because it is very gentle , you go with the method because its not rushed its slow focused and relaxing , no fear of been in pain . I feel i became more of aware of my body .

8. I am hopeful that clinical massage could play a positive part in pain management. The hands on approach helped me to relax and better manage ongoing pain. I also feel that the process, especially with a repeated treatment is a helpful tool for proprioception. Especially as someone with a new diagnosis, this was really helpful for me to actually tune into what was going on in and my body and where. It helped me to make a more conscious effort/awareness of my posture and how I was sitting/holding myself out of treatment. I'd also be really interested to see more about the links between treatment specifically with neck, shoulders and head and helping things like dysautonomia. Again I am still early into my diagnosis journey but did find that the treatment helped to slightly reduce the prevalence of vestibular migraines and general dizziness. When they have occured, I have felt more in control of my body with a better understanding of what might be causing them.

9. I defo think it has a very important part to play as it treats the whole body and not just one joint, which is what you often get when you see a physio. But with Ed's you need to look at the whole body

Q5. What have you gained/learned by taking part in this study?

1.The importance of giving me some me time

2.I have seen the value in regular self-care even if just because I notice the difference it makes when I engage in this. I have gained some confidence in following and attending to a treatment plan as it really does help when I make myself put in the time this takes. When I'm in a better head space hopefully I can pursue a positive routine of self-care and massage treatment for my physical and emotional well-being.

3. I knew that my body needed extra help and support to begin to be able to move again and make steps towards healing but I couldn't find what that intervention was. What I learned during this study was that there is an intervention that my body finds immensely helpful and I am incredibly thankful to have found it.

4. Ive learned to take time to focus on my health and will want to continue with it as it had a physical benefit for me

5. Better ability to calm and relax my body even for a short while

6. I have gained and learned so, so much from taking part in this study - I am so glad and grateful for the opportunity to particpate. I think it's probably fair to say that I may have had a slightly unique experience during the study - which led me to a deeper exploration of my own relationship not just to my ongoing pain management, but spiritually as well. I feel like a different person having participated in the study, compared to the person that first started. In the best of ways. It really was an incredible and eye opening journey, one that I am extremely grateful for.

7. The importance of looking after my body, that massage works. Breathe works - do work.

8. I have learnt a lot but the most hopeful things have been to be more in tune with what has been going on with my body. I think I have subconsciously been using avoidance for a while, especially with not knowing what was going on. Having a combination of a new diagnosis and massage treatment has allowed me to finally tune in and consider what is actually going on. This has helped me to know where to be more careful, what to splint. And equally, has reassured me of what a good day can look like which has made me slightly less scared of exercising and trying new things. I was really interested to learn about fascia and how this can look different with EDS. The approach of treating the whole body to benefit a specific part (like my hands) has been very helpful and interesting. It has made me thing about what holistic things I can do to support myself by treating the whole picture as opposed to just feeling frustrated with a specific limb that hurts to touch.

9. The importance of listening to your body

Q6. Do you have any suggestions for improving this study in the future?

1.Maybe a group discussion or chat room to share thoughts and tips and create solidarity

2. No, my obstacles to participating were largely fatigue levels meaning the journey alone was substantial and at times impossible - but this isn't something I'd expect others to try to overcome on my behalf.

3. I think it might be helpful to change the way that improvement is scored. During this study we used a pain scale that scored pain based on everyday activities like being able to walk upstairs. I wonder whether the scoring could focus on something like function as opposed to pain. I’m not sure what that would look like but what I noticed was that I was struggling to get the scores to reflect my improvement because it wasn’t necessarily that my pain reduced, but my function improved and I’m thinking that over time, as my function continues to improve, pain reduction should follow it it might take much longer.

4. No

5. Include shoulders and arms too- these are delicate for me but also the largest source of my pain so would be interesting to see the effect

6. I think the only thing I would change is making it an hour long session.

7. currently no

8. I can't think of anything, I'm just grateful for the opportunity!

9. Not that I can think of

Q7. This is an opportunity to provide any general feedback (eg. running and design of the study, symptom management it may offer, where it fits as part of HSD/EDS care more generally etc...)

1.Such a little thing, but the app was tricky to fill in on a phone

2.You were friendly, warm and welcoming and I'm grateful to you for all your time and care going into this study. I think it's wonderful you're doing this and I hope many others can benefit as I have.

3. I think this work is essential to improving quality of life for hEDS and as a pathway to being able to access integral movement that many of us just couldn't get on the conveyor belt of. I would like to see the study go further and wider but would need to think about what I feel that would look like. Perhaps a longer study that goes beyond the basic package of self care and further into treating specific (as well as wide spread) muscular skeletal difficulties in hEDS patients. I'm guessing particular areas of difficulty could be focused on in particular cohorts as well as looking at the wider impact and improvements in our bodies in general, when one particular difficulty is worked on.

4. I really enjoyed it! I had no issues. I felt like it catered to those with these conditions. Questions felt like the right things to understand. As I have flare ups on certain body parts I would use the massage in conjunction with specific physio if I had any specific issues or problems, but would hope this type of massage would help me not flare up as much

5. Thank you for letting me take part!

6. My only feedback here would be that the weekly pain outcome questionaires were tricky to answer as the scales just didn't feel like quite the right fit - in a week where I'd maybe have a few days of pain, but fine the rest, I struggled to figure out where to pitch the average score to. I feel like those questionaires perhaps could have benefited from more detail. Though it may make the process longer for everyone involved, I feel like a daily measure would have been more useful.

7. could this be study been presented to gp practices that have teaching opportunities as options that have been researched as a treatment safe for EDS.

8. I am very hopeful that this will play into EDS care some day and that there will be more education in the future around holistic care. I understand it might be tricky to keep it as quantitative, but if you ever wanted to collect qualitative data I think mini voice notes or videos could be a good tool, and maybe accessible for people with dyslexia etc.

9. (left blank)