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An individualized yoga programme for multiple sclerosis: a case study

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Abstract

Purpose

Despite the evidence that yoga is beneficial for people with multiple sclerosis (MS), substantial in-depth qualitative studies of yoga and MS, in particular individualized yoga programmes (IYP), are lacking. The aims of this paper are a) to conduct a case study on an IYP for one participant with MS in terms of their experience of yoga and how yoga affects their particular symptoms of MS and b) to better understand the unique and changing needs of someone with MS in the context of an IYP.

Design and Method

A qualitative case study design with data collected via a participant diary completed over the 24 week duration of IYP; an exit interview after the final IYP session, and weekly records completed by the yoga teacher. Data were analysed using thematic analysis.

Findings

Over the course of the IYP the female participant experienced an increased awareness of negative thoughts and feelings about MS and how it affected them and their body. As the programme progressed she began to work through these feelings and by the end of the programme reported experiencing improvements in muscle tone, strength, balance, psychological well-being and confidence.

Conclusion

Our findings highlight the importance of a programme individualized to meet the complex health and psychological needs of an individual with MS.

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Introduction

Multiple sclerosis (MS) is the most common neurological condition affecting approximately 100,000 people in the UK. MS can cause a variety of symptoms which vary between individuals and across the duration of an individual's illness. Typically symptoms include: fatigue, pain, muscle spasms and stiffness, and can affect balance, memory, sensory systems, bladder and bowel functioning, emotions, speech, swallowing, vision, and women's health problems (e.g. menstruation and menopause). There is currently no cure for MS but symptoms can be managed through medication, diet, exercise and complementary therapy (<http://www.ncbi.nlm.nih.gov/pubmedhealth/PMHT0024311>).

Yoga is commonly used by people with MS and users often report it as being extremely helpful for their condition (Esmonde & Long, 2008; Page, Verhoef, Stebbins, Metz &, Levy, 2003; Yadav, Shinto, Morris, Senders & Baldauf-Wagner et al. 2006). For example, a UK survey found that yoga was one of the most popular Complementary and Alternative Medicine (CAM) therapies used by people with MS; 31% of participants had used it over the past year and over 80% of them rated it as either 'helpful' or 'extremely helpful'. Specific benefits of yoga described by participants included enhanced ability to relax, physical symptom relief such as improved balance, mobility, flexibility, muscle strength, and reduced spasticity, and increased social contact (Esmonde & Long, 2008). A US survey of 2026 people with MS found that 23% had used yoga and 16% meditation. Yoga and meditation were considered the most beneficial CAM therapies with 52% and 46% of participants respectively rating the therapy as "very beneficial" (Yadav, Shinto, Morris, Senders & Baldauf-Wagner et al. 2006). Important to note is that MS, in addition to being a neurological condition, is chronic, progressive, or, remissive, and each individual may present with different symptoms such as flares, tremors, and depression, that in themselves

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can fluctuate and vary daily. This has important implications for yoga therapists working with people with MS and any similar condition in respect of being flexible in their approaches, sometimes working impromptu, to reflect the unique needs of each individual when choosing the appropriate asanas, breath awareness exercises, pranayama, relaxation, and meditation techniques.

The amount of research that has been conducted on yoga and MS does not reflect the high level of use and the potential benefits for people with MS. Two small randomized controlled trials (RCT) have been conducted. Oken, Kishiyama & Zajdel et al. (2004) randomized 57 people with MS to one of three groups for six months: Group 1 attended a weekly yoga class with home practice, Group 2 attended a weekly exercise class using a stationary bicycle with home practice, and Group 3 were allocated to a wait-list control group. Both active interventions produced an improvement in fatigue compared to the control group, but not in attention, alertness or mood. However, the authors concluded that because of the small sample size the study was underpowered, thus the absence of statistically significant effect for mood and cognition needs to be interpreted cautiously. No adverse events related to the interventions were reported. Velikonja, Curić, Ozura & Jazbec (2010) conducted an even smaller RCT, with 20 people with MS receiving either sports climbing, or Hatha yoga, for 10 weeks. Results showed that compared with the climbing group participants practising yoga experienced an improvement in their selective attention performance. There were no improvements in mood, spasticity and fatigue.

Physical exercise has been shown to alleviate MS symptoms (Rietberg, Brooks, Uitdehaag & Kwakkel, 2004) and its use is recommended in U.K.s NICE (National Institute for Health and Care Excellence, 2004) guidelines for managing MS. Research also suggests that yoga can be considered an equivalent to conventional exercise (Yadav & Bourdette, 2006) and may be more acceptable than exercise to people with MS (Yadav, Shinto, Morris, Senders,

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Baldauf-Wagner et al. 2006). A recent review of the literature comparing exercise and yoga indicated that yoga may be as effective as, or better than, exercise at improving a variety of health-related outcome measures for both healthy and diseased populations (Ross & Thomas, 2010). Finally, meditation (an integral part of yoga) has been shown to reduce perceived stress among people with both MS and cancer (Pritchard, Elison-Bower & Birdsall, 2010). This is important for people with MS given that 78% report that stress intensifies their symptoms (Simmons, Ponsonby, van der Mei & Sheridan, (2004).

Substantial in-depth qualitative studies of yoga and MS and studies of individualized yoga programmes (one-to-one sessions between teacher and client) are lacking. RCTs in this area are small and have only focussed on a limited number of outcomes. Studies suggest the benefits of yoga to people with MS may be far more rich and complex than the limited outcome measures used in RCTs. Benefits may include improved flexibility and self-management, valued relationship with practitioner, increased awareness of body and stress levels aiding stress and symptom management, pain reduction, spiritual experiences, and peacefulness (Franklin, 2002; Mayer, 1990). Further, few studies have explored the experience of yoga in the context of emotional and psychological wellbeing among people diagnosed with MS.

A systematic review of the research evidence on the effectiveness of yoga for MS recommended that qualitative studies should now be conducted in order to understand the experience of people with MS who use yoga and to assess the feasibility of yoga as an intervention for people with MS (Richardson, Freeman, Smith & Pilkington, 2005).

Exploratory qualitative studies are essential in order to understand the subjective meanings of yoga to each individual (e.g. yoga as stress relief, symptom management, or a life philosophy), individual perceptions of how yoga affects their MS, what it's like to practice yoga with MS, and the limitations of yoga. Gaining an understanding of these issues will have multiple benefits, including providing information for people with MS (and yoga

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teachers) on how yoga may be helpful to them, what they can expect from practicing yoga and the limitations of yoga. The experiences associated with behaviour can provide new insights that may impact on the efficacy of future individualized yoga programmes for people with MS (Bulley, Payne & Mutrie, 2009). Gaining an understanding of these issues will have multiple benefits for people with MS, yoga therapists, and others working with and for people with MS. The aims of this paper are to report on a case study on an individualised yoga programme (IYP) for one participant with MS, in terms of their experience of yoga, how yoga affects their particular symptoms of MS and to better understand the unique and changing needs of someone with MS in the context of yoga delivered on a one-to-one basis. It is important to note that 'yoga' including the IYP is not a cure for MS, rather it may help people to cope with life and help to manage the symptoms experienced with MS more effectively.

Material and Method

The Individualized Yoga Programme (IYP)

The IYP is based on Hatha yoga, guidance from (Fishman & Small, 2007) and influenced by the teachings of the renowned BKS Iyengar. Hatha yoga emphasizes the development of strength, stamina, suppleness, balance, concentration, and relaxation. It helps to promote general physical, psychological and spiritual health and well-being, and as with all forms of yoga, it addresses the whole person. The IYP for the case study reported here was delivered over a six month period; 24 weekly sessions each of 60 minutes duration. The first session is an initial consultation followed by weekly sessions to include: postures (asanas) individualized according to the participant's needs, symptoms and ability, and ends with relaxation. In addition, sessions incorporate breath awareness and meditation. A programme of home practice to complement each session is provided. An IYP (as opposed to a class programme) ensures that asanas, relaxation, breath work, and meditation meet individual needs, and enable the home practice information to be tailored to the individual participant.

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The yoga sessions for this case study were conducted at the yoga teacher's, Lesley Powell's (LP), home.

Case study: a humanistic approach

This paper presents a qualitative case study design, analysed using thematic analysis to provide a rich source of data about a person experiencing the varied and fluctuating symptoms brought on by MS in the context of an IYP. Giving priority to the human meaning to the experience has the potential to highlight challenges and offer new insights that cannot be identified by quantitative standardised quality of life outcome measures alone.

Demographic information (e.g. age, sex), medical history and aims of attending the IYP were collected at the first IYP session (i.e. Week 1). Data on the participant's experience of each session and the following week were collected using weekly progress records completed by LP at the beginning of each session, a participant diary, and an exit interview conducted at the end of the final IYP session (i.e. Week 24). The purpose of the weekly progress records were to record asanas, relaxation, breath work and meditation techniques used, observed changes in the participant, and reported changes by the participant. The participant completed a diary of home practice for the duration of the study (i.e. Week 1 to Week 24). The purpose of the diary was to gain the participant's narrative of their experience of yoga during the IYP. The participant interview was conducted by LP after the final session and lasted approximately 30 minutes. The purpose of the interview was to gain the participant's overall experience of the IYP.

Data from the diary provided a rich narrative of one person's experience of yoga in the context of the IYP. Using narrative as a method of data collection is essential to gain the subjective, self-reflective and personal experience of participants; it allows participants to tell their story without influence of specific questions or theoretical bias (Murray, 2000). Using narrative in this way reduces potential interpretation bias and provides a window to observe

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and gain insight into the personal reflections, changes, and emotions that may otherwise be lost.

Data from the weekly progress records, participant diary and exit interview were analysed using thematic analysis (Braun & Clarke, 2006). Thematic analysis was chosen for its flexibility in the process of data coding, analysis and interpretation, and simultaneously enabling the researcher to identify patterns and themes within data sets. Using an inductive approach (i.e. bottom-up) ensures the themes are data driven, from which patterns and themes can be identified for the purpose of disseminating information (e.g. in specialised training of yoga teachers who wish to work with people with MS, to relevant organisations, and to gain a better understanding of the benefits of using a IYP for people with MS). Data from the weekly progress records, participant diary and exit interview were read and re-read to gain familiarity of the data and then coded using the primary aims of the study [i.e. experience of the IYP for people with MS, physical and psychological/emotional changes, yoga methods used]. Each sub set of coded data was then grouped into themes for further analysis and interpretation.

Data from the consultation (Week 1) provided descriptive information and formed a baseline from which changes could be monitored. The participant's name is changed to protect anonymity. Consent was obtained from the participant for the undertaking and publication of this case study.

All qualitative data collected was analysed manually using colour coding, annotations of scripts and pen diagrams to help organise data and identify themes and subthemes.

Results

Demographics

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At the time of the case study, Mary was aged 37, single, and worked full time and was diagnosed with relapsing-remitting multiple sclerosis (MS) at the age of 26 by a senior medical specialist in MS. Mary was taking a weekly injection of Beta Interferon – Avonex to keep relapses under control and lessen the attacks; she had been on this medication for three years. Mary's MS may be considered as mild in severity and remissive in nature.

Mary had been treated for depression taking a six month course of anti-depressants and periodically experienced irritable bowel syndrome. No symptoms and/or side effects were reported as a consequence of either the anti-depressants or Beta Interferon. Due to the MS, Mary reported experiencing difficulties with stool movements and often felt 'uncomfortable'. Although Mary reported that her general physical health was 'okay' with no hearing, vision, bone or spinal concerns at the time, she expressed concern that her energy level was low (feeling constantly tired), compounded by twitching in both legs at night that kept her awake. She also reported that her left leg felt heavy and after walking short distances tended to 'drag', and often felt unsteady when going up and coming down stairs. Overall Mary was quite conscious of these limitations in mobility and how it impacted on her social activities and social life. Mary's biggest fear was that her situation would continue for the rest of her life.

Aims of participation in the IYP

Mary's aims of participating in the IYP were physically oriented. They included helping to increase strength in her legs, improve balance, become generally more active and lose some weight. In Mary's case, balance was described as weakness of the muscles worsened by walking too far, dragging leg, tiredness, and tremors.

Although Mary, at the time of the IYP, attempted to go to a local fitness centre for exercise, this was sporadic. Mary had tried astanga yoga one year prior to attending the IYP. However, Mary stopped going after two classes as she was unable to move through the

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postures as quickly as other attendees, subsequently this reduced her confidence in the ability to participate in any yoga class.

Mary's story

Enhanced awareness: physical, emotional, cognitive

During the first month of attending the IYP Mary began to develop an enhanced awareness of her body's physical limitations, and of the emotions and thought processes in relation her body. She acknowledged the difficulty in accepting MS, the anger felt towards her body, and resentment of how these feelings and thoughts affected her body image. This enhanced awareness of the physical limitations imposed by MS, the impact MS was having on her psychological and physical health and wellbeing, and general approach to life as she quite succinctly described:

“Just a continual feeling of being depressed and wanting to cut my body in half and squash it!”

During the first month of attending the IYP Mary felt challenged and experienced a setback with MS; she described her legs as being ‘*very wobbly and feeling heavy*’ that impeded her mobility. She began to identify other areas of her body that she described as being “*weak*”, particularly arms and shoulders. In addition to the enhanced physical limitations, Mary experienced emotional challenges too. She described becoming aware of the anger and frustration felt towards her body that affected her whole body image, persona, and general health and wellbeing.

Enhanced knowledge; adaptations, breath awareness, and affirmations

However, Mary's attitude, outlook and determination, enabled her to view this enhanced awareness positively by helping her to understand ways to improve the practice of yoga.

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Taking on the advice and encouragement provided at each yoga session, Mary was able to turn her anger into action, making subtle adjustments to her body to become more relaxed and comfortable in an asana. For example, in response to Mary's anger and frustration with her body and its limitations when moving in and out of postures, LP encouraged her to *'be kind to her legs, her body, and herself'*, and to *'transform feelings of anger into love'*, and at the end of each session *'thanking her body for being co-operative'*.

During this period, gentle encouragement was given to Mary to raise awareness of the breath to enter and exit each asana, and when in the final position. This helped Mary to recognise when she was holding her breath, notably during the postures she 'disliked', such as Trikonasana, Warrior, and Vkrasana; these postures highlighted what she described as the *'imbalances'* and *'weaknesses'* in her body, emotions, and mind. As the IYP progressed, Mary was able to continue with making adjustments. For example, she compensated for the *'wobbliness'* she experienced by hyperextension of the knee joints as this helped her balance. Thus, Mary was requested to *'soften'* her knees during postures (which actually accentuated the *'wobbliness'*) and to re-focus her energy flowing toward her feet as, rather than directly to her knees and the sense of *'wobbliness'*. Repeating postures using this strategy appeared to work well for Mary; she noticed that her legs were less *'wobbly'* and less likely to *'collapse'* during a posture.

"Understanding my disability, enabled Lesley to break down the postures in a simplistic way that allowed me to achieve each posture in a safe and confident manner. Analysing my body's strengths and weaknesses, Lesley created an effective monthly program of yoga enabling me to practise postures at home to increase strength and flexibility on a daily basis, which has been fundamental in my progression in yoga. ... Through Lesley's dedication and knowledge of teaching yoga for specific needs and addressing personal goals, I have seen a vast improvement in my body."

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This awareness was the pre-cursor to improving her practice. On acknowledging the issues, she was able to re-focus and make the necessary changes to her thought processes and to her breath when entering, holding, and exiting postures with 'relaxed' effort (key to yoga practice). As a result, the anger and frustration with her body she had previously experienced lessened.

Table 1 presents the individual's experience of the IYP ordered around the themes presented in the results section.

<insert Table 1 here>

Home practice

Mary's home practice during the first three months was intermittent. However, this process of 'irregular' yoga home practice served to increase Mary's awareness of the differences between when yoga was practiced and when it was not practiced daily. As a result Mary's home practice became more consistent, forming part of her daily morning routine. This regular home practice combined with the continued progression on the IYP was rewarded with a noticeable improvement in her body tone, posture, strength and balance, with the additional benefits of enhanced self and social confidence to undertake another activity – swimming, and to take more rests when out with friends.

"When yoga is practiced (with awareness) there is a sense of feeling better physically, emotionally, and mentally with a sense of calm that filters into daily activities..... climbing up, and coming down stairs, and walking for longer distances, yet recognising when to stop and rest rather than struggle on and wanting to hide. I have joined a fitness centre and started to go swimming, and now acknowledge the need to stop and take short rest breaks when out shopping with friends. ...I have seen a vast improvement in my body when medical opinions said that my decline was a natural progression of the disease."

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Although Mary admitted to still '*getting angry*' with her body and particularly toward her legs when they felt like '*collapsing*', she remembered the advice given to her in the sessions; to re-focus this energy to her feet and concentrate on developing strength and steadiness.

This altered mind state and re-focusing of energy appeared to help overcome any feelings of anger and resentment towards her body.

By the end of the IYP Mary was surprised and pleased to observe noticeable improvements in her physical strength, stamina, and balance, all of which were personal goals for participation in the IYP.

"All together the yoga sessions have helped boost my morale, attitude, and outlook on life."

As well as being valuable to the case study, self-reflection and keeping a record of changes as they became apparent was an important part the process. Having the space to reflect on changes proved to be insightful and part of the healing journey that takes place during any yoga practice (swadhaya - the act of self-study). Importantly, knowing when to 'stop' in any activity, including yoga, is essential for both the teacher and pupil to recognise.

Discussion

The aim of the case study reported here was to discover the experiences of one person with MS participating in an individualized yoga programme (IYP) in terms of physical and psychological health and wellbeing. Mary's primary goal of attending the IYP was physical in nature, and although initially home practice was intermittent and challenging, often dictated by her social and work life, as Mary began to experience physical improvements this encouraged her to include yoga as part of her daily routine. The increased body awareness that Mary developed has been observed in other studies on people with multiple sclerosis

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who practice yoga (Franklin, 2002; Mayer, 1990) as has the improvement in MS symptoms (Yadav, Shinto, Morris, Sender & Baldauf-Wagner et al. 2006).

In addition to the physical goals achieved, Mary reported that the IYP raised awareness to the negative emotions of anger, frustration, and resentment, felt toward her body, and subsequently her body image, that inhibited her social life, and activities. By the same token, this awareness also helped Mary to overcome them, thus illustrating the psychological gains experienced during the IYP that enabled Mary to initiate making changes to her daily routine and social life in general. As a result of the gentle encouragement, and support offered by LP during the IYP, Mary was able to re-focus her anger and become more 'mindful' of her approach to each asana and to yoga, further illustrating some of cognitive benefits gained over the course of the IYP. The importance of such self-evaluation and reflection are essential in the process of change. As Prochaska & DiClemente (1983) and Prochaska & Velicer (1997) suggest in the process of change model, increased awareness, emotional arousal, social reappraisal, environmental opportunities (yoga), and self-reappraisal, are the experiential aspects of this change process from which the more overt behavioural changes can begin to take place. Interestingly, keeping a participant diary for the research also became a valuable self-reflection tool for Mary. As Kolb (1984) described, we learn through experience, but only if we process that experience and make sense of it.

Denial and avoidance of the more negative and sometimes painful aspects of life are in the longer term neither helpful nor healthy. The fact that Mary began to realise that since receiving the diagnosis of MS she had a total disregard for her body, living primarily in her 'mind' and being very self-critical suggested the beginning of a healing journey. The acknowledgement of inwardly held emotions such as anger and fear is a remarkable insight to how MS can affect individuals and to the importance of the yoga teacher's support during this critical stage of growth, awareness, and throughout the healing process. Yoga is a transformative practice, as opposed to solely an 'exercise' practice, and with correct use of

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postures, breath awareness, relaxation, and support, can be a gentle way to overcome our deepest fears and deeply held emotions. This apparent personal growth combined with the improvements Mary reported in physical health and improved symptoms (e.g. strength and balance) suggest there is potential value for yoga to help overcome some of the challenges faced by MS. Previous research has shown that exercise alone may help to improve functional impairment though not quality of life, thus yoga may serve to provide an 'all round' means to help overcome some of the emotional and physical symptoms associated with MS (Franklin, 2002) and (Mayer, 1990).

Clearly, regular home practice proved to be beneficial to Mary and ultimately it was Mary's persistence and self determination to improve her situation, health and wellbeing. It also suggests to the importance of gaining the trust and respect between yoga therapist and participant, developing a good relationship, within the context of an individualized yoga programme as suggested by (Franklin, 2002 and Mayer, 1990). MS is a complex condition with many symptoms that can vary daily and affect people in different ways. Yoga therapists may need to be aware of potential side effect/symptoms that any prescribed drug can cause within a therapy context. Further with regard to balance, understanding the probable cause and primary concern is important. Balance for people with MS is a complex symptom, can vary daily, may be the result of multiple causes such as weakness, tremors, tiredness, infection, and may involve sensory input, processing, and output (<http://www.ncbi.nlm.nih.gov/pubmedhealth/PMHT0024311>).

It was not the aim of this case study to undergo a thorough medical examination, rather to listen to the participant's experiences of MS as part of a qualitative study. In terms of any physical and psychological concerns expressed by the participant it is Important to understand what these concerns are and mean to the person, that is, how it affects them, how they currently manage them, what makes them worse (i.e. walking too far, trying to

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keep up with friends, and not taking rest stops), and/or better. People that experience MS may require encouragement, and as such yoga practice may be better when tailored to any physical limitations. Further, people with MS may need 'patience' in waiting for improvements from regular yoga practice, and as such the development of enhanced mind-body awareness is an important component of an IYP.

Caution/limitations

The study is based on one person's story and therefore cannot be generalised to all people diagnosed with multiple sclerosis. Six month is a very short term in 'yogic' terms; yoga is a life-long study. This study was done without external funding, using the experience of LP as a researcher, and available resources (willing participant) therefore there are limitations to sample size, duration, methodology, as well, cost considerations and time to analyse all the data manually. The first author, LP, implemented the IYP and conducted the qualitative data collection, analysis and interpretation, therefore potential bias of results. Thus, research evidence using a more rigorous design and mixed methods (qualitative and quantitative) is necessary to ascertain the essential benefits of yoga for people with MS, types of MS, and stages of MS and determine whether a IYP is beneficial indefinitely (or not) for people with MS.

Conclusion

With regard to yoga, the study supports the literature suggesting yoga has potential physical benefits for people with MS and may be a means to help cope and manage some of the symptoms associated with MS. With regard to evaluation, research continues to favour the 'medical' model of evaluating interventions with specific physiological outcome measures such as depressed mood and symptomology. A humanistic approach allows those diagnosed with MS and participate in yoga research to elucidate their views and experiences that may be omitted from RCTs yet may provide valuable insights to the process of change.

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Future research may benefit from using both qualitative and quantitative methodologies with specific outcomes measures to determine the value of yoga for people experiencing MS, particularly in the longer term. The more research that is undertaken, the more likely it will be that external funding bodies will support larger and wider research projects.

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Table 1: Results showing key themes, subthemes and keywords

| Themes | Sub themes | Key words |
|-----------------------|--------------------------------------|-------------------------------------------------|
| Enhanced awareness | Physical limitations | Wobbly/heavy legs, fatigue, weakness |
| | Emotional feelings/thought processes | Anger, resentment, body image |
| | Cognitive | Persona, general health |
| Enhanced knowledge | Adapting asanas | Moving slowly, and in stages into/out of asanas |
| | Breath awareness | Dislike of asanas |
| | Affirmations, encouragement | Re-directing negative energy |
| Regular home practice | Social confidence | Taking rests, self-pacing |
| | Social activities | Swimming |