

Introduction

Sheffield Yoga for ME/CFS offers specifically-adapted remedial yoga sessions to people with ME/CFS to sufferers within Sheffield and its surrounding areas.

Myalgic Encephalomyelitis is an incapacitating chronic illness, often resulting in sufferers being unwell for many years. For many only a very small number of activities are manageable, both socially and physically, due to the multiple and severe symptoms of the illness. They experience loss of income since they become too poorly to work, and they become socially isolated as they are often largely housebound, thus the impact of the illness on sufferers' lives is profound.

The yoga sessions offered by the group are carefully considered to meet the requirements of people with this debilitating illness, to provide important physical, social and emotional support to members (project users) who wish to attend the yoga. Ordinary yoga would be too strenuous to sufferers and would overlook the important needs of sufferers. There are no other tailored yoga classes available to those with the needs of those with ME/CFS in Sheffield.

Specially trained yoga tutors adapt their teaching to focus on gentle, often lying postures and breathing and relaxation. The yoga sessions are run twice a week, with different types of yoga available (Hatha yoga and Iyengar yoga). The contrasting styles, different venues and alternative times of day sessions are held, enable the yoga to be accessible to number of people with ME/CFS. The yoga venues are warm and quiet, with disabled access together car parking nearby. The Iyengar yoga takes place in a specialist yoga centre where all the necessary equipment is available. Due to the loss of earnings to many sufferers because of the condition, an optional donation for session attendance is suggested, thereby helping those experiencing financial hardship.

Such members are also able to benefit from the free transport provisions (either funded taxis or volunteer drivers), which enable those with limited finances and those who are too unwell to drive or cope with public transport.

New members to the group receive a free information pack about the yoga sessions and other information on yoga and the group provisions. Regular informative newsletter bulletins are sent to all members who wish to receive them, either through the post or electronically.

The group website (www.sheffieldyogaforme.org.uk) contains information to members about the yoga available at the group sessions as well as other information on yoga for ME/CFS. Members also have access to a lending library allowing them to borrow resources for home yoga practice.

Sheffield Yoga for ME/CFS is a registered charity (Registered Charity Number: 1117464) and most of the Trustees/Management Committee who help to organise the yoga and are responsible for the running of the group have ME/CFS resources. Additionally, several non- ME/CFS affected volunteers have important roles.

Formal Monitoring Questionnaire for Yoga Session Attendees

During the autumn months of October and November 2017 Sheffield Yoga for ME/CFS conducted its annual formal monitoring exercise as in previous years. This took the form of an optional short written survey that was available at the group yoga sessions for regular attendees (more than three sessions) to complete.

This formal monitoring helps to assess whether the group's main aims/outcomes are being achieved:

- Delivering services and provisions that satisfy project users' (members) requirements
- Determining whether the desired aims and outcome for the project/group are being fulfilled
- Identifying potential improvements to current services offered by the project/group

The previously identified outcomes and aims of the project took the foundation of the survey questions.

Full text of key questions:

- Do you find the social aspects of the yoga group helpful?
- Do you find the yoga has a positive effect on your wellbeing (how you feel & function, e.g. mood, confidence, self-esteem, happiness)?
- Do you think the yoga helps you to manage your illness better (e.g. by helping to achieve the right balance between rest & activity)?
- Do you think the yoga practice has led to any improvements in your symptoms?
- Have the yoga classes, bulletin, website or library helped with home practice of yoga or relaxation (please leave blank if you do not practice at home)?
- How useful do you find the following group resources: Website; Bulletin; Yoga & relaxation CDs/Books/Tapes

Overall, twenty-one yoga class/session attendees completed the written survey, thereby providing the group with their invaluable feedback on the yoga sessions and other services provided by the group. The information given from these was analysed as below.

Potential yoga class/session attendance outcome	A great deal	Quite a lot	Slightly	Not at all
1. Social benefit	39%	22%	33%	6%
2. Positive effect on wellbeing	76%	19%	5%	-
3. Better management of illness	52%	43%	5%	-
4. Improvements in symptoms of illness	29%	29%	38%	5%
5. Helped with yoga or relaxation practise at home (to those whom applicable) *	17%	39%	44%	-

*14% responders did not practice at home, of the 86% of people that did

The usefulness of resources to surveyed	A great deal	Quite a lot	Slightly	Not at all	Percentage of

yoga attendees (where applicable)					Responders Applicable
Newsletter Bulletin	27%	55%	18%	0%	52%
Website	40%	40%	20%	0%	48%
Lending Library of CDs	30%	60%	10%	0%	48%

Percentages have been rounded to whole numbers for simplicity.

Written feedback from Responders on Questionnaire Forms

Responders were invited to make comments on the back of their completed survey forms. These people gave positive feedback and highlighted the degree of the appreciation of the yoga and provided together with its importance

To quote some examples of the written feedback from responders:

- ❖ “The teachers are fantastic – very understanding. Volunteers appreciated.”
- ❖ “I was so down and lonely before I started yoga but now I have found yoga I have noticed a great deal of improvement in my moods. I now know I am not the only one that has this illness so I don’t feel so isolated. I have also met some lovely new people I wouldn’t have done before. So thank you very much.”
- ❖ “The yoga classes are an essential tool in helping manage my M.E.”
- ❖ “Been a great help over the last few years. I know I should come more often!”
- ❖ “New – very positive & kindly attitude. Lovely environment. Very helpful – thanks.”
- ❖ “The relaxation, meditation helps massively along with gentle stretching that keeps limbs moving without over exertion leading to crashes. Having teachers that understand long term conditions is a positive/must. Thank you.”
- ❖ “I find the yoga an essential part of my illness management. I couldn’t do without it. It is so important to have gentle remedial yoga classes available as I would not be able to attend normal classes as they would be too strenuous.”
- ❖ “Yoga is wonderful to help M.E! I’m so grateful for funding to support this group.”
- ❖ “When I don’t attend regularly I don’t feel as well. People are very friendly. The relaxation sessions are very beneficial to health. Suggestions: please could yoga teachers introduce themselves at the start of each class; Christmas raffle; Christmas social.”

Discussion of Results

Overall the information provided by the formal written survey feedback is positive and lends support that the desired outcomes/aims by the group/project are being fulfilled, by offering multiple

benefits through the yoga and other group provisions by largely meeting members (project users) largely needs and requirements.

Attendance at the yoga sessions provides an opportunity for members to engage with others in some social activity, this can be very important for some members who often are very isolated due to their chronic illness, with 96% of the responders found attendance at yoga socially beneficial. Over half (61%) found it beneficial to either a 'great deal' or 'quite a lot' of an extent, but for most (39%) the extent of benefit was 'a great deal'. Attendees appreciate having the opportunity to have social contact with others who experience similar symptoms and hurdles due to their chronic illness. Some attendees are so unwell they find it difficult to interact with others since ME/CFS affects their cognitive ability making conversations hard work, therefore the current social benefits are less, but they are grateful for the opportunity in the future.

All those surveyed reported that they found the yoga has a positive effect on their wellbeing, for most (95%) this positive effect on their wellbeing was either to 'a great deal' or 'quite a lot' of an extent. Even more encouragingly the degree of benefit to the majority (76%) of attendees' wellbeing was found to be 'a great deal' of benefit. This is another important benefit from yoga attendance especially when having such restricted daily living due to the condition.

The yoga the group provides was also found to enable attendees to benefit from better management of their condition with all attendees reporting this benefit, for 95% this benefit was either to 'a great deal' or 'quite a lot' of an extent, which is very positive. It is even more encouraging that over half of attendees they found the benefit to their health management was 'a great deal' of an extent. This highlights that the special tailored yoga provided is ideal for attendees to achieve the balance between not using up all their energy reserves (as typical yoga sessions would) and allowing enough activity to benefit their body through adjusting their activity due to their body's needs at the time. For ME/CFS sufferers this fine balance is important to learn when engaging in any activity; learning this allows them to tackle daily activity in a more manageable way (sometimes simple tasks can be a big challenge to an ME/CFS sufferer) with less of an impact on their already limited health. This benefits/outcome from yoga attendance as with the social benefit will have a big effect on these members lives and the way in which they contend with the challenges even just daily life can bring when having a chronic illness.

That specifically-adapted yoga provided benefitted (95%) the attendees surveyed through leading to improvements in their symptoms. It is encouraging that this main desired aim/outcome of the group is being achieved through symptom improvement and reported by most attendees surveyed; most of the attendees questioned (56%) the benefited their condition a 'great deal' or 'quite a lot' from the yoga. The biggest degree category of benefit for most (38%) was found to be 'slightly' beneficial improvement in symptoms through yoga attendance. This is an important benefit from the yoga since the myriad of symptoms can be very incapacitating and affect multiple bodily systems so even just a slight ease in symptoms will be greatly welcomed by attendees.

Over three-quarters (86%) of yoga attendees questioned stated they practice yoga and relaxation techniques at home, aided through yoga session attendance and other service provisions offered by the group. For over half (56%) their extent of home practice was to either 'a great deal' or 'quite a lot'. This desired outcome achieved through the groups services/aims highlight just how beneficial yoga and relaxation is to sufferers, so much that they want to participate at home. The group is

delighted that the yoga sessions and provisions continue to gain attendees benefits at home.

The formal written survey also assessed the usefulness of the group resources that are accessible to project users/members to the questionnaire responders. All of those who use the group website (48% of responders) (www.sheffieldyogaforme.org.uk) found it useful; with for 80% of responders this was equally to either “a great deal” or “quite a lot” of an extent. Some attendees may be too unwell to use the internet and therefore are unable to use this resource.

All those surveyed who optionally chose to receive the information newsletter bulletin (52%), either through the post or email, find its contents useful. The degree of usefulness was either ‘a great deal’ or ‘quite a lot’ for 82% of those surveyed who receive it. Nearly all those questioned (90%) who use the lending library of yoga books and CDs resources (48%) find them ‘quite a lot’ or a ‘great deal’ useful thereby enabling them to continue to gain benefits at home. The website was found to be useful to all those questioned who use it (48%), for most this was ‘quite a lot’ (60%) and for some (30%) it was ‘a great deal’ useful.

The specially adapted yoga and other service provisions available to members/project users cannot be over emphasised, especially considering the dearth of beneficial and accessible alternatives available to sufferers. The importance of the above achieved outcomes through yoga attendance and provisions should not be overlooked, especially when taking into consideration the dearth of available and accessible alternative provisions and beneficial therapies (NHS and private) to people suffering with ME/CFS, as well as the significant detrimental impact the condition has on sufferers’ health leading to restrictive daily living.

The yoga provided by the group is not only tailored to benefit sufferers’ condition, but also other requirements members will have such as needing accessible and quiet venues with parking nearby and an a sessional assistant available to help with bags and equipment. The free transport provisions available enable more members to attend the yoga since it enables all members who wish to attend not be constrained by transport needs or costs (some are too unwell to drive and/or find public transport has too much of detrimental effect on their condition). The accessibility to all members is extended due to the voluntary donations from those who can afford them.

Furthermore, the resources provided by the group intentionally to involve all members/project users through outreach to those too poorly to attend the yoga sessions, by making them feel included and encouraging the with the potential goal of future yoga session attendance once their symptoms allow them to.

The group/project provisions really make a difference to the lives of members/project users and the importance of this should not be overlooked since this group of society is overlooked by beneficial, affordable and accessible provisions.

The wider Sheffield community also benefits from the project through volunteering opportunities. Current the group has four volunteer drivers who drive members too and from yoga sessions. Not only do the members appreciate having a regular driver but the drivers themselves appreciate enabling sufferers to attend the yoga, to engage with other people as well as benefit potentially health wise. The overall running of the project enables members (and others) to volunteer their

skills in a manageable and flexible way to a group that is understanding of their condition and needs. These understanding roles are rare for members to find. All volunteers gain better wellbeing through assisting others. Furthermore, the group believes that the families and carers of members who attend yoga benefit also through seeing the benefits their family/friend gains through yoga attendance.

Conclusion

Members are fortunate to attend these therapeutic, easily accessible and available yoga sessions. All the yoga tutors are specially trained and sympathetic to members requirements. The yoga helps various symptoms and is very relaxing. The social aspect is key also since some members do not make it out of the house, let alone to socialise other than class attendance. The transport provisions enable yoga session attendance with as little effort as possible and without affecting their limited incomes.

The positive questionnaire findings support that the project provisions meet the desired project aims/beneficial outcomes expected. The social opportunities available at yoga sessions were reported to be beneficial to many of yoga attendees questioned (96%). All the yoga attendees reported that the yoga enabled them better illness management; this was 'a great deal' for most (52%) and 'quite a lot' for 43% of attendees surveyed.

Additionally, all the yoga attendees also felt that there was a positive effect on their wellbeing; for some (19%) this was 'quite a lot' but most (76%) this was 'a great deal' of an extent.

Yoga attendees also reported improvements in the symptoms of their illness; either a 'great deal' or 'quite a lot' for and for most the symptom improvements were slight (38%).

All the resources made available to were found to be useful to all attendees who used them; for the lending library was useful to 90% of attendees to either 'a great deal' or 'quite a lot' of an extent, for the website these extents were reported by 80% of attendees.