

Results of Monitoring conducted by Sheffield Yoga for ME/CFS in Early 2013

Introduction

Sheffield Yoga for ME/CFS runs remedial yoga classes for people with ME/CFS. This is a serious debilitating chronic illness and people are often ill and disabled for many years. The consequences of this are profound in terms of loss of income and social isolation. In many cases, very few activities, social or otherwise, are possible for people because of the severity of their illness.

The classes are carefully organised to meet the needs of people with this illness and provide important social, emotional and physical support for members of the group. The provision of yoga classes specifically for people with ME/CFS is not available elsewhere in Sheffield and ordinary yoga classes are unsuitable for most people with ME/CFS.

Specialist remedial yoga teachers run the classes, who are well experienced at teaching yoga to ME/CFS sufferers. There are two styles of remedial yoga available; Hatha yoga (Friday mornings) and Iyengar yoga (Tuesday afternoons). The varied approaches, different venues and class times open the classes to a number of people with ME/CFS. The premises for the yoga are quiet and warm. There is parking next to the buildings and the venues have disabled access. The Iyengar yoga classes are held in a specialist yoga centre, where all necessary equipment is provided. However, the number of attendees at Iyengar classes has been variable and so a trial period to open these classes to groups with other illnesses, which present with similar symptoms was started in March 2011, in conjunction with the management of Sheffield Yoga Centre.

A profound consequence of the illness is loss of earnings. Classes are free to those attending, but donations to the charity are encouraged from those able to pay.

Many people with ME/CFS are too ill to drive or use public transport and the provision of taxis or lifts from volunteer drivers make the classes more accessible to a greater number of people. This is an important use of the group's funding.

The group provides regular bulletins by post, information on the website (www.sheffieldyogaforme.org.uk) and resources such as yoga books/CDs/tapes, which are available from a postal library. These resources are available to all those on the mailing list. Previous surveys have consistently shown that this aspect of our service is highly valued by the large majority of members.

Sheffield Yoga for ME/CFS is a registered charity. (Registered Charity Number: 1117464). The majority of trustees who organize the classes have ME/CFS, but there are also several able-bodied volunteers who do an invaluable job.

Monitoring of Class-Attendees in Early 2013

Sheffield Yoga for ME/CFS regularly performs a monitoring exercise to enable to group to check and ensure that the following aims of the group are being achieved:

- Providing a service that meets members' needs
- Identifying areas where the service may be improved
- Ascertain whether the group is achieving the outcomes the group /yoga sessions aspire to achieve.

During part of January and February 2013, some group members who attended classes completed a short survey. These members had attended the yoga sessions held by the group at least three times. As well as general information about demographics of the class, the survey also focused on previously identified aims and these were used to construct key six questions. The monitoring exercise resulted in seventeen surveys being completed. The surveys were analysed and the findings are as follows.

	A great deal	Quite a lot	Slightly	Not at all
1. Social benefit	44 %	19 %	38 %	0 %
2. Positive effect on wellbeing	59 %	29 %	12 %	0 %
3. Better management of illness	59 %	29 %	12 %	0 %
4. Improvements in symptoms of illness	29 %	41 %	29 %	0 %
5. Yoga or relaxation practise at home	12 %	47 %	35 %	6 %
6. Which available resources attendees find useful:	Lending library of CDs/tapes		Website	Bulletin
	24 %		59 %	41 %

Percentages are rounded to whole numbers for ease.

Full text of key questions:

1. Do you find the social aspects of the yoga group helpful?
2. Do you find the yoga has a positive effect on your wellbeing?
3. Do you think that yoga helps you to manage your illness better?
4. Do you think that yoga practice has led to any improvements in your symptoms?
5. Do you practice yoga or relaxation techniques at home?
6. Which of the group's resources do you find useful?

Comments made by responders on survey forms:

- "Trinity Church Hall is a lovely venue for the Millhouses yoga class - light and airy plus good facilities close to the hall. It is brilliant having yoga teachers who have such a good understanding of our ME/CFS and adapt their classes to meet our needs and teach us good breathing techniques and relaxation methods which are beneficial to our condition."
- "Fabulous yoga!"

- “The bulletin is essential as not online.”

Verbal feedback from attendees at classes:

“It is very important that the yoga sessions continue because they are very beneficial to me, particularly as there are no other services like it in the area for the condition.”

Summary of Findings

This year’s survey findings have proved very positive as in previous years. This is encouraging as it means the previously identified aims of the yoga classes are continuing to be achieved. The socialising opportunities available at the classes have enabled all members to overcome the social isolation that has resulted from, often many years of, chronic illness. All the surveyed class attendees found the social opportunities beneficial to some extent, with 63% reporting a large effect. The group has enabled these social opportunities to be easily accessible to members through the provision of taxis and volunteer drivers to enable class attendance easier for members. The provision of volunteer drivers and taxis is a very important one, as some members are too ill to drive or to manage public transport. Additionally, as loss of earnings is often a profound consequence of the illness, it is important that the group funds both taxis and volunteer driver fuel mileage and a voluntary minimal donation is accepted for class attendance. This is so no members are exempt from attending classes due to restricted income.

All of the class attendees surveyed found that the yoga offered at classes had a positive effect on their wellbeing to some extent; with a majority (88%) finding it had a large positive effect. This is a particularly important achievement of the classes, because due to the nature of the CFS/ME sufferers often feel particularly unwell and such opportunities to gain increased wellbeing are often rare. Furthermore, all those surveyed found that the yoga classes enabled them to manage their illness better to some degree. Sufferers walk the fine line of achieving a balance between doing enough activity so that muscle deterioration does not result, but also so that they do not overexert themselves so that negative impacts result. This management of the illness is imperative because if sufferers undertake too much activity beyond their limits, this can result in deterioration of symptoms or even chronic relapse. It is very positive to find that the majority of attendees surveyed felt that the yoga classes helped them to achieve to a large extent better management of their condition (88%). This will have had a significant impact on the way they manage daily life. Additionally, it is also significant to find that most of the class attendees surveyed (70%) found that the yoga led to large improvement in their symptoms. None of the class attendees surveyed found that the yoga did not lead to an improvement in their symptoms to at least some extent. This is a very positive finding that all members surveyed found some relief in their symptoms due to class attendance, particularly when the symptoms can be very restrictive and challenging to manage.

Overall, it is particularly reassuring and encouraging that all members surveyed found the yoga provided, improved their wellbeing, their illness management and an improvement in their symptoms to some extent at least. The yoga class aims are being met and are having positive effect on attendees’ ME/CFS, wellbeing and additionally, help to overcome the social isolation attendees often face.

Since the service the group offers is not available elsewhere in Sheffield the significance of the classes for ME/CFS sufferers cannot be stressed enough. This was particularly highlighted by the verbal feedback from a class attendee who stated about the lack of service provisions in the area for ME/CFS sufferers and hence it was important that the classes continue.

The yoga classes have been carefully organised in order to meet the needs of people with such a debilitating illness in the best way. Specialist remedial yoga teachers teach the classes. In their adaptation of their yoga teaching, they focus on lying postures in order to minimise energy consumption and strain on the body. The teachers also gear the yoga towards breathing and relaxation techniques, these are beneficial to sufferers because the breath is vital in producing energy and it is important sufferers can relax to ease tension in the body. The monitoring also found that some attendees surveyed also practice yoga at home, so they must find it beneficial to their illness to also practice outside of the classes. Both venues for the classes are also chosen for the suitability towards ME/CFS sufferers. They are warm and quiet, with convenient parking next to the buildings. Both the appropriateness of the nature of the class in one of the venues was highlighted a by a comment from one of the members surveyed (see comments on survey forms). It is important to the group that such requirements are adequately catered for for members, in order to make the classes accessible to them.

The group provides three different types of resources to both members who are able to attend classes and to those who do not attend. Of these resources, the website is particularly popular, with 59% of members surveyed finding it useful. This is possibly because members can refer to it to keep up to date with information, such as the dates of classes, which teachers are teaching and other information, e.g. snow issues. The regular paper bulletin is also very popular with members; this may be because some members are too poorly to access the internet. Therefore, the paper format received through the post makes the class information more easily accessible. The importance of this is highlighted by a comment from a surveyed member (see comments by surveyed members) who is not online. The lending library of books and CDs of yoga techniques continues to be found a useful resource by the class attendees surveyed. Therefore, the group will continue to offer these resources to members.

Class Non-attendees Monitoring and Findings

A further survey was conducted of members who do not attend the classes. A sample of non-attendees were telephoned and asked if they minded answering some questions on the group resources and yoga for ME/CFS classes. Nine non-attendees agreed to participate in the survey (unfortunately, some ME/CFS sufferers are unable to manage speaking on the phone well or do not have the cognitive function to manage on the spot questions very well.)

The questions asked and the results of the survey are as followed:

Question	Yes	No	Not Applicable
Do you find the bulletin useful?	100 %	0 %	-
Do you find the website useful?	56 %	0	44 %
If you are not well enough to attend the classes, is yoga a goal for when you are a bit better?	78 %	0	22 %

These results further support the usefulness of resources to all members, both to those who manage to attend classes and those who do not. The results suggest that the paper bulletin really is often invaluable to those who are unable to attend classes, as all the class non-attendees surveyed found the bulletin useful. In comparison, just over half found the website useful, with those who did not with stating that this is not applicable to them, possibly because they are too unwell to use the internet. Furthermore, the results show that the majority of non-attendees (78%) were reassured that once they are well enough there is a tailored service available that they can access, with the class attendance acting as a future goal. Two of the members surveyed had previously attended the classes and were considering returning, should a volunteer driver be secured for them. We have found that some members prefer the reassurance of a volunteer driver, rather than dealing with taxi firms each time they wish to attend classes. The prospect of more class attendees is heartening. Securing volunteer drivers for these members is now a goal that the group can aim to fulfil.

Conclusion

The findings of the monitoring conducted by Sheffield Yoga for ME/CFS in early 2013 have proved positive for the group. Those regularly attending classes found the social aspects of attending beneficial and the majority reported a large positive effect on their wellbeing. The yoga classes also permitted attendees better management of their illness and additionally, lead to improvements in the symptoms of their ME/CFS. It cannot be emphasised enough how important these benefits are for sufferers, particularly with the debilitating nature of CFS/ME. It is also very important too, given other beneficial services/treatments are so limited and difficult to access. All the three contrasting resources available to both class attendees and non-attendees are all found to be useful to members. Those who are unable to attend classes are reassured by the ongoing hope that they will one day be able to attend the classes. Thereby, our project offers the prospect of a more supported future to people who are marginalised and who are often inadvertently excluded from mainstream services. The group is very encouraged and pleased to report that the previously identified aims of the yoga classes continue to be achieved.