



SUSSEX
MS CENTRE
small charity, big impact



Annual Review 2018

Our Centre

The Sussex MS Centre is a vibrant community run by and for people with Multiple Sclerosis (MS).

Our Centre was opened in 1984 by people diagnosed with MS and their family members. We provide peer support, therapies and group activities that help us to meet the challenges of living with this long term condition. We are based in Southwick, and serve the whole of the Sussex region.

Our Mission

Our mission is to improve the mental and physical health, well-being and life chances of people in Sussex living with MS.

Our Values

- **Members.** Our members and their carers are at the heart of everything we do.
- **Volunteers.** Our volunteers are valued and supported, as well as being encouraged to develop their knowledge and skills.
- **Teamwork.** Members, volunteers and staff work together.
- **Respect.** We treat everyone equally with dignity and respect.
- **Environment.** We provide an inclusive, welcoming and safe environment.
- **Community.** We foster peer support and participation.

Who else do we support?

As well as serving the MS community and their carers, we also welcome those with other chronic neurological conditions and have members with conditions such as Cerebral Ataxia, ME, Lyme's and Cancer. We also have members who are Stroke survivors. They too can feel very self conscious and vulnerable and benefit both physically and psychologically from being included in the range of accessible activities that we offer at the Centre.

Welcome to our Annual Review of 2018

Chris Ash-Edwards, Chair of Trustees

Welcome to our review of 2018 in which you will see how much we do to improve the lives of people living with Multiple Sclerosis and those who care for them.

The departure of both our full time staff at the end of 2017 could have seriously affected our operations. However, the commitment of our many volunteers, particularly Alan Taylor (who retired as Centre Manager in 2014) ensured that services continued as normal whilst we sought new staff.

Ben Bloom took up the post of Centre Manager in January, joined by Emily Dixon as Operations and Events Coordinator in February. Unfortunately personal circumstances led to Ben leaving us in June. We are very grateful for the fresh energy he brought and the hard work he did resolving outstanding administrative and governance issues. In November, Emily-Jane Stuttard joined us as Centre Manager so we are starting 2019 with a full team. Our thanks go to our Development Manager Jane Taylor for increasing her hours and responsibilities when necessary over the last eighteen months.

We are excited to have progressed our plans to replace our aged prefabricated buildings with purpose built premises. Oxygen Treatment remains in high demand as its effectiveness is becoming more widely recognised. Our ambition is to increase our provision in the new building with a larger chamber. In the meantime we have trained more Bara chamber operators which has enabled us to increase the number of sessions that we can provide. Trustee Martin Bennett completed the training at the London Hyperbaric Centre at Whipps Cross and is now our lead operator. We have continued to provide many therapies and classes for our members to access, while also responding to our members' suggestions for additional classes and treatments while ensuring these services remain at the same high quality and are affordable for those on a low income.

During the year Derek Aitken, Christopher Fox Walker and Nikki Manchee stood down as Trustees, and we thank them for their service contributions. We welcomed Peter Cook to the Board. We continued to meet bi-monthly. We also have a Finance Sub-Committee and a volunteer led Social Committee that meet bi-monthly. Our Centre continues to be user led, and we discuss our members feedback at every Board meeting, responding accordingly. This is also supported by the fact that the majority of our trustees who are also members live with MS themselves .



Board of Trustees

Our Board of Trustees has a range of relevant knowledge and skills. Two thirds of them have MS, while the others are carers or regular volunteers.

All of our Board members are frequent visitors to the Centre, interacting with members and staff. This gives them a good insight into the varying needs of the Centre.



Alison Clough



Martin Bennett



Chris Ash-Edwards



Peter Cook



Virginia Keefe



Jill Brookes



Alan Taylor

Alan resigned from the board on 25th July, but continues to act as Company Secretary.

Alison Clough "I have been a member of Sussex MS Centre since 2005, when I was first diagnosed with MS. I attend the keep fit and pilates classes and for a special treat I have manicures and massages! I previously worked for Brighton and Hove Council as a Nursery Manager with experience in health & safety, safeguarding, managing staff. My main role on the Board is looking after Centre membership."

Martin Bennett "I am the senior chamber operator, and I carry out training sessions for operators with the help of Alan Taylor. I have been a trustee for at least 7 years, and I would really like to help improve the Centre for our members."

Chris Ash-Edwards "I have been a member of the Centre since 2001. I am a Chartered Accountant with extensive financial and general management experience mostly in container shipping, I retired in 2005, and have been a Trustee since 2014, currently sitting as Chair of Trustees."

Peter Cook "I am a retired senior Royal Naval Officer having served Queen and Country for 35 years. I became a member of the Centre when I was diagnosed with MS 10 years ago and have used the oxygen chamber weekly throughout that time. Now retired I feel that I am able to give something back to the Centre in a way which I hope will enable the Centre to move forward by using my life skills and my understanding of MS."

Virginia Keefe "I was diagnosed with MS in 2001, and have been a member of the Centre since 2005, and a Trustee since 2011. I am a Registered Osteopath. I work at the Centre, a Medical Centre and various Natural Health Centres and have taught Osteopathy, Seated Exercise, Shiatsu and Chi Gong. I attend the Centre for Oxygen Therapy, Pilates, Voice work, Beauty Therapy and occasionally Acupuncture and Therapeutic Massage. I became a Trustee because I felt I could contribute to the Centre from a Business, Health and Safety and a holistic point of view"

Jill Brookes "I ran a small business for over 20 years providing services to higher education and social services charities. After my retirement my best friend, who has MS and is a Centre member, asked me if I could help with the bookkeeping. Subsequently I joined the Board and then became treasurer. I currently have responsibility for HR."

Centre Staff

Centre Manager

Emily-Jane Stuftard (EJ)



EJ worked previously in the Arts & Education, coming from Friends Centre Brighton (Adult Education centre), where she was manager for the past 11 years.

Development Manager

Jane Taylor



Jane retired from teaching after being diagnosed with MS in 2001. She has worked part time at the Centre since 2003.

Events & Operations Coordinator

Emily Dixon



Emily joined the Centre in 2018 and organises the fundraising events programme for the Centre, alongside supporting EJ with the day to day running needs of the Centre.

A little bit about Multiple Sclerosis

Multiple Sclerosis is a disease of the Central Nervous System (CNS) which occurs when, for unknown reasons, the immune system attacks the myelin sheath which protects the nerve fibres. This leads to scarring and slows or prevents signals travelling along the nerve. It is variable and unpredictable.

People with MS have varying needs, depending on the pattern, duration and aggression of their disease. Common problems amongst our members are a decline in mobility and flexibility, eyesight and cognitive problems, fatigue, bowel and bladder dysfunction and a risk of developing secondary disabilities as a result of poor muscle use.

There are many reasons why people living with MS can suffer from loneliness and anxiety. People may feel self conscious and the lack of confidence to go out into the wider community, or be reluctant to make demands on their friends or carers, and feel that it is simply easier to stay at home. It can lead to severe depression as well as other health risks.

Our Community

Peer support and access to up-to-date information are invaluable tools for improving the health and welfare of those who use the Centre. Our members are often reluctant to be 'a nuisance' so gaining information during informal chats and browsing our library in their own time, or attending one of our drop-in sessions, is very useful. NHS services are available for times of crisis, but at the Centre it is possible to learn strategies to alleviate symptoms, access useful affordable drug free therapies, keep up with current research, find out about state entitlements and new treatments and even share suggestions about good holiday destinations, all of which are essential for improving the circumstances of those with MS and their carers and families.



In 2018 to encourage peer support and to ensure our members were well informed we

- opened every weekday except for bank holidays and the Christmas period
- ensured a member of staff or volunteer was available to welcome every visitor and that the Centre was comfortable and welcoming, with light refreshments available at all times
- hosted weekly drop in socials with volunteers providing additional snacks and sandwiches, including a Monday morning 'Craft Class', a Tuesday 'Coffee Morning', and the trial of a monthly 'Vegan Lunch'
- held nine formal 'out of hours' social events, with entertainers and catering
- provided advice and information from our trained volunteer benefits team to over 30 disabled people and their carers to identify and access statutory support
- liaised with other MS charities and support services, displaying their literature on current research, drug therapies and other life enhancing services
- sent three newsletters (The Belle) out to all of our members with information on what's on at the Centre, and articles of interest
- hosted a lively Facebook page



Oxygen Therapy

We have operated our Oxygen Chamber since 1984. Oxygen Therapy is a simple, non-invasive and painless treatment; the user sits in the chamber, which is then pressurised, and breathes pure oxygen through a mask. This increased pressure, combined with an increase in oxygen to 100 percent, dissolves oxygen in the blood plasma and in all body cells at up to 10 times normal concentration.

Many of our members find the treatment really helps them manage their symptoms, reporting improvements in fatigue levels, it provides symptom relief and speeds recovery after attacks limiting the damage to the nervous system. We have also had remarkable success from people with problem wounds, diabetic leg ulcers, sports injuries, bone fractures, some dermatological conditions, radiotherapy necrosis, and peripheral neuropathy.



In 2018 over 4500 Oxygen Therapy sessions were attended at the Centre.

Our core membership donate what they can towards the cost of this treatment. For those who use the chamber to help with other long term chronic conditions we suggest a donation of £16 per treatment. Sports injuries bring in valuable income paying a minimum of £23 per session.

The chamber is operated by a team of 17 trained volunteers, and we run between 4 and 5 sessions every weekday.

By the end of 2018 the chamber was operating at virtually full capacity.

Richard

Richard was diagnosed with MS over 25 years ago. He started coming to the Centre in 2017 after a severe relapse meant that he had to give up his full time work.

"I started coming to the Centre to use Oxygen Therapy. I had an intensive course of around twenty sessions in the first month, and now use Oxygen Therapy once a week. I find the Oxygen really helps me with my fatigue, and on weeks that I am really struggling I will often book an extra session in the chamber."

As well as Oxygen Therapy I come along to the Tuesday Keep-Fit class each week which is taken by Lynne. Because Lynne has MS herself, I really feel that she completely understands my limits, and so although she will push me, she has great consideration of how far I might be able to go in each class.

It is the socialising that I think really brings us all back each week though, knowing that we are all there to help and support each other during the class, and having a well-earned cup of tea, a natter and a good laugh after the class, really is the best medication you could ask for!"



Keeping fit and active together

It can be hard to be consistent in your exercise regime when you live with a condition that is so variable and presents such a wide range of challenges. Participating in group activities is great for encouraging us to keep moving and feel positive. At the Centre, we offer a range of group activities to enable our members to participate in a way that suits their circumstances and to target their particular disabilities. We hold at least two exercise classes every weekday, a total of 13 classes over the week. Our members can choose from Yoga or Seated Yoga, Pilates, Keep Fit, Physio-Gym, Tai-Chi and Voice-work Classes. In 2018 we also added weekly drop-in Belly Dancing and Alexander Technique classes to this choice, both of which have proved popular.



Yasmin

Yasmin has been a member of the Centre for over 20 years; she first visited us on the recommendation of a friend who used the Centre regularly. For the last 8 years Yasmin has been a part of our dedicated team of volunteers, running the Reception desk on a Wednesday, counting the coins from our collection boxes and coordinating our volunteer Benefits Team the rest of the week.

"I use so many of the classes at the Centre, coming to weekly sessions of Pilates, Keep-fit and Tai-chi. I have gone to exercise classes elsewhere where I have felt really left behind, but the class teachers at the Centre are so in tune with all of our individual abilities and have a real understanding of MS meaning that I never feel like I'm the only one struggling!"

The Centre has given me so much over the years, and so volunteering regularly is my way of giving something back."



Improving wellbeing and managing symptoms with individual treatments

We have three small treatment rooms at the Centre, for which therapists pay a nominal rent to offer treatments to our members. Our members suffer from a wide variety of symptoms so we offer a range of therapies to address each individual's needs.

Therapies are chosen to provide symptom relief, help ward off secondary disabilities and improve wellbeing.

These treatments are available Monday to Fridays between 9am and 4.30pm. We offer Shiatsu, Reflexology, Deep Tissue Massage, Physiotherapy, Beauty Therapies, Chiropody, Indian Head Massage, Alexander Technique, Acupuncture, Osteopathy, Reiki and Counselling.

Our therapists develop an understanding of MS and can seek advice from our staff and neuro-physiotherapists with any concerns. They are self employed and charge between £15.00-£20.00 per session. We assist members in particular need with these costs as necessary.

Over 2800 individual treatments were attended in 2018



Eva

Eva has been working as a massage therapist with the Centre since 2016 and dedicates two days a week to work with our members.

"I get so much from working with members that use the MS Centre; I offer treatments to those living with MS and their Carers. Seeing some people making leaps in their mobility and the difference that massage can make to the wellbeing of members is what motivates me.

I incorporate a variety of different styles into my therapy, and although massage based, I work freely to identify the specific needs of the individual, taking a deep but not necessarily strong approach to treatment, which is particularly suitable for people living with MS.

This practice was inspired by my own injuries and illnesses, and I have a particular interest in restructuring balance rather than superficially relaxing the body, which is something that can be hugely beneficial to people living with MS.

Working with the MS Centre is so special as it gives me the opportunity to use massage therapy to help empower people to manage their lives."



What else happened in 2018?

New Logo

We finalised the new Sussex MS Centre logo design with the help of Centre member Georgia Richardson. With this new logo in place, we have re-branded our Centre leaflets, the road sign at the end of Croft Avenue, and our Centre sign at the front door.



Our new logo, with thanks to member Georgia Richardson for helping to push this forward



Our newly branded road sign

Co-op Community Fund

In 2018 the Co-op in Southwick supported the Centre in a variety of ways, including funding new chairs for our Oxygen Chamber. The Co-op in Southwick has now chosen to support the Sussex MS Centre as one of three chosen charities in their Community Partnership, and will be continuing to support us throughout 2019.



Co-op Southwick manager Rob, presenting EJ & Emily with a cheque to replace the chairs in our Oxygen Chamber

What else happened in 2018? *continued*

Social Events

We aim to put on approximately one social event a month. 2018 saw us hold a Burns Night event, a St Patricks Day Stew, a Quiz & Fish n' Chips night, Pub Games evening with support from Bedlam Brewery, an afternoon Cream Tea, a Summer barbeque, a 60s night, and a Christmas Dinner.



Worthing Steel Band at the
Summer Social barbeque

August 2018

Fundraising Events

We held a series of fundraising events during 2018 including a sponsored walk and sponsored cycle ride organised as Centre events. Independent fundraisers included a barbeque organised by a Centre member with support from the Freemasons. We held a supermarket collection at Tesco- Holmbush, a Centre member cycled the Prudential Ride London, to raise funds for the Centre, and Haywards Heath branch of Lloyds Bank supported us as their charity of the month during September.



Riding along the river Adur
Fundraising Bike Ride

June 2018

Raffles

We held two incredibly successful raffles over December 2018. Albion football player Dale Stephens donated a shirt signed by the whole team. This raffle was in addition to our annual Christmas raffle, which, with some fantastic prizes donated to the Centre was a very effective fundraiser.



Signed Albion T-shirt for Raffle

December 2018

Carers

Those of our members whose disease pattern has been quite debilitating often come to the Centre accompanied by a carer. We offer our services to carers on the same terms as our members as they too can be vulnerable to isolation and stress related illness.

Most carers don't take treatments but enjoy a short break or relaxing here with others, sharing friendship, information and advice. Peer support and friendship are invaluable for improving the health and circumstances of the carer, and we encourage carers to join us for social events. Family members of those with MS can also access our services for advice and support.



Volunteers

Without the support of our many volunteers we would not be able to offer such a large variety of services, and we are enormously grateful to them for all of their commitment.

Our volunteers provide a first point of contact staffing the reception. They operate the Oxygen Chamber, help with book-keeping and administrative tasks, and assist with providing refreshments and giving a warm welcome to everyone who visits. We also have a volunteer team dedicated to offering benefits and financial advice, and another team that organises and runs our social events and helps with fundraising.

Many of our volunteers are Centre members who enjoy putting their knowledge and skills to use in a supportive environment.



The team of Lloyds bank volunteers who gave up a day in August 2018 to plant up the Centre garden.

Behind the masks are our volunteer Oxygen Chamber operators Dom & Pete getting festive in December 2018



Alan and Martin volunteering their time to marshal our annual sponsored walk in September 2018

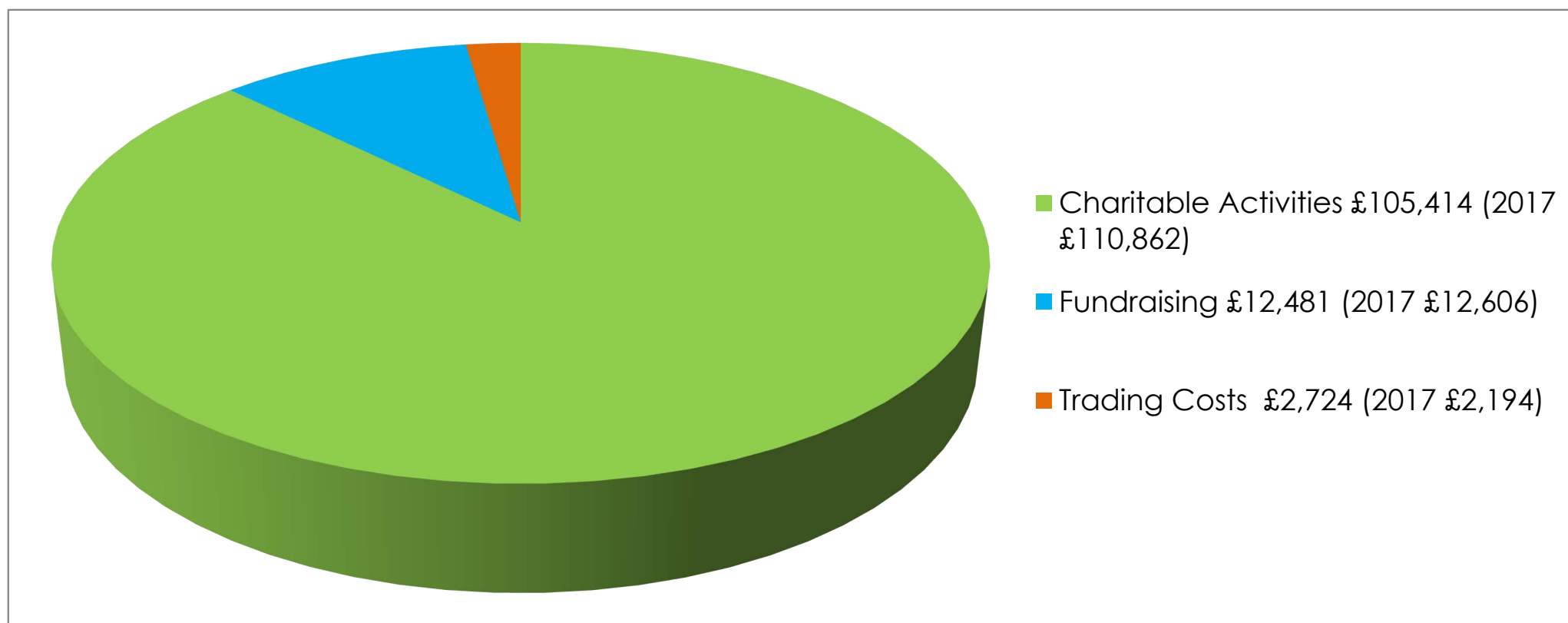
Facts and figures

Accounts for 2018 are currently being audited in preparation for our AGM in May and these figures are based on our internal draft accounts.

The deficit in 2018 was largely due to staff changes which resulted in a reduction in fundraising activities during the year. There has also been a significant reduction in income from collection boxes due to the increase of 'plastic' money.

Expenditure

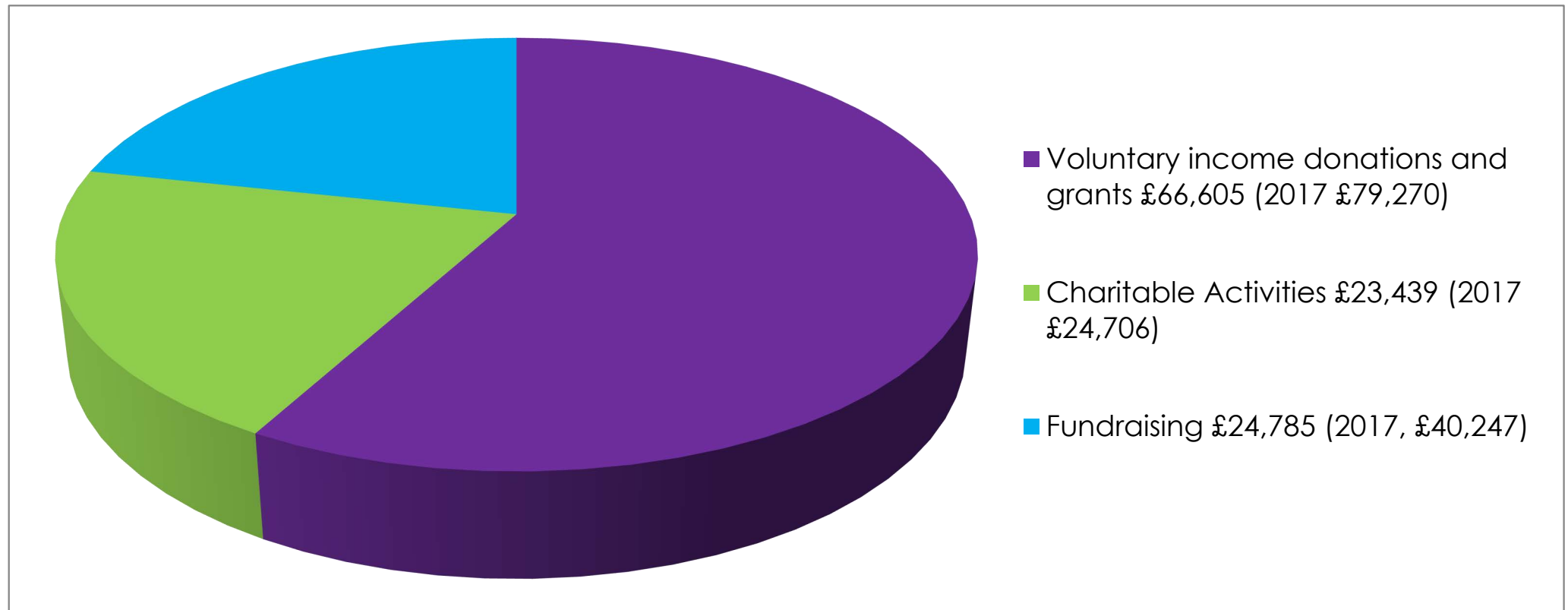
Total resources expended in 2018 £120,619 (2017: £125,662)



Income

Income amounted to £114,829 (2017: £144, 223)

We receive no funding from statutory bodies, and have a wide variety of streams of income to support our Centre. Our members give what they can for the services that they use and apply their energy and enthusiasm to organise many fundraising activities and events. We are thankful that our Centre attracts donations from community groups, charitable trusts and local companies. We are also grateful to those who remember us in their wills or give in memory of their loved ones. We encourage 'monthly giving' and have coin collection boxes at many sites around Sussex.



How we improved in 2018

New therapies and classes

In response to our members' suggestions in our comments books, in 2018 we added Belly Dancing and Alexander Technique to our weekly schedule of drop-in classes.

Trustees notice board

We responded to some members' concerns in regards to communication between the Board of Trustees and our members by creating a Trustees notice board in the social area of the Centre, along with a Trustees letterbox, which members are encouraged to use if they want to write directly to the Board.

Bookings System

We moved over to 'Northwood'-our new online system for making bookings and managing Centre contacts. Northwood is tailored towards its use in MS Centres, and recommended by MS National Therapy Centres (MSNTC).

Data Protection

We have updated all systems and procedures to ensure we are fully compliant with the Data Protection Regulations that came into place in May 2018.

Community outreach

Jane met with the Mid-Sussex care coordinators in order to reach out further into the community.

Benefits Team

Our dedicated volunteer Benefits Team helped 39 different members over 50 sessions in 2018. Cognitive difficulties that often come with MS mean that form filling can sometimes be difficult. Our Benefits Team is an incredibly important and highly valued part of the support that we provide at the Centre.



Rebecca Rees
Alexander Technique



Galit Mersand
Belly Dancing

Key goals for 2019

- To launch our 'Raise the Roof' building project, which is detailed further in this review
- To identify any skills gaps within our board and recruit new trustees to this effect to strengthen our ability to deliver our mission (following on from 3 trustees stepping down in 2018)
- To continue to respond to suggestions and concerns by encouraging our members to give feedback both verbally and in our comments book
- To continue to ensure our financial stability and update our book-keeping to online software
- To continue to increase the provision of our Oxygen Therapy sessions by recruiting and training new operators
- To create, design and launch a new updated user-friendly website
- To further develop our use of Social Media increasing greater awareness of the centre and developing our networking with other organisations
- To improve communications with statutory agencies that support people with MS
- To increase the range of therapies and classes on offer

The logo for 'RAISE the ROOF' is located in the bottom right corner. It consists of the words 'RAISE', 'the', and 'ROOF' stacked vertically. 'RAISE' and 'ROOF' are in a bold, dark blue, sans-serif font, while 'the' is in a smaller, red, lowercase, sans-serif font. The text is set against a solid light blue rectangular background.

RAISE
the
ROOF

Thank you

We value every contribution that is made toward our income and our heartfelt thanks go to every individual, event organiser, community group and charitable trust that has helped us over the last year. We are also so very thankful to those who choose to remember us in their will or give to us in memory of a loved one.

Our dedicated team of volunteers ensures that we are able to open our doors each day, and we thank our Chamber Operators, Receptionists, Benefits Team, and all other volunteers who have given their time either regularly or one-off to help the Centre.

To all of our independent fundraisers, and to everybody who took part in Centre organised fundraising events, to those that have swum, run, cycled, walked, sky-dived and much more for us, thank you!

The Sussex MS Centre simply could not exist without so many people coming together and helping in their different ways, and for that we are very grateful.



Exciting times ahead!

The Sussex MS Centre was first opened in 1984 at Southlands Hospital in Shoreham. We moved to our current site in 1994, purchasing second hand prefabricated units to house our Oxygen Chamber, a couple of small therapy rooms, a communal area and an office. At the time, we offered Oxygen Therapy, one weekly yoga class and a limited number of physiotherapy, chiropody and beauty treatments.

In 2007 we added an annex, and in 2009 we refurbished and insulated the old units. These improved premises dramatically increased demand, so, responding to our members' needs and requests we began to offer more activities and a wider range of therapies and treatments to help to improve the health and wellbeing of the people of Sussex with MS, as detailed in this review.

We are now operating at virtually full capacity, and have been developing our plans to improve the facilities at the Centre by replacing our elderly prefabs with purpose built premises. A recent meeting with Adur and Worthing Council indicated their full support in moving forward with our building project, and we will be working with Stewart Henton, the architect who took us through adding our annex in 2007 and refurbishment in 2009.

Our vision for the future of the Sussex MS Centre is to have an up-to-date, modern, airy new building with more space for our exercise and classes area; a larger Oxygen Therapy provision, ideally doubling our capacity; an accessible kitchen fit for purpose for all of our members; a space for meetings, and the possibility of a hydrotherapy pool. Many MS Centres around the country have replaced their original portakabins, so we know that it is achievable. We look forward to creating a new purpose built premises for the Sussex MS Centre.

Sussex MS Centre

Southwick Recreation Ground

Croft Avenue

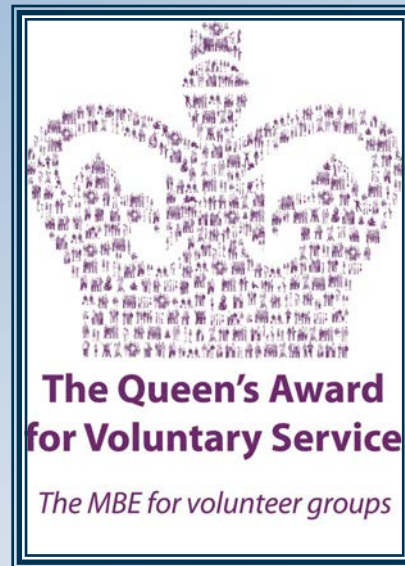
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