

Travelling Dementia Suitcase



To date our staff alone have delivered 54 sensory activity workshops across Southampton, Portsmouth and the IoW to a total of 752 people with dementia. This figure does not take in to account the number of additional sessions delivered by our expanding army of volunteers who are using sensory based activities on a daily basis. So, the figures in reality are much higher than reported here. Embedding the Think Sense message into everyday life has been an immense help for carers who are also our volunteers. They report knowing the scientific basis behind sensory activities has helped improve their compassion fatigue.

Annual Report 2019

*‘That was the best fun I have had in years
Took my mind off all my worries’*

The response to delivery of this project has been overwhelming. As you can see from the impact figures, much larger numbers than expected are benefitting from knowing more about changes in sensory deprivation and taking part in relevant activities. We have a waiting list for training for volunteers that already exceed targets for year two and all our current volunteers are embedding fun based sensory activities into their caring.

Partnerships with care homes, Alzheimers and Memory Cafes has enabled this fantastic reach. In addition, training 56 volunteers to deliver Think Sense activities has ensured longer term sustainability of the model. Those 56 volunteers are not only delivering sensory sessions but are also spreading the message much wider to family, friends and other carers through a snowball effect.

Measuring Impact

As part of our evaluation process we undertook structured Observational Analysis of the sensory activities we are delivering direct to people with



Taking in to account physical limitations and stage of dementia journey, our ethnogram research shows engagement looks like this:

Smiles, eye contact, active movement, head up, looking alert, singing the words, making the appropriate movements, finger tapping, laughter, whooping, cheering, mouthing the words, shoulder movements, jesting, joking with each other, stamping feet, copying others, putting down drinks to take part, remaining in room, eyes sparkling, hand dancing, chatting, encouraging others, showing pleasure at results, crying due to labile emotions, not showing frustration i.e. in trying to express a word they can't remember, reaching out to hold a hand, conversations, dancing, holding a group rhythm, more active movements as session progresses, focused even if for short period of time.

Non engagement looks like this:

Sleeping, hand wringing, rocking, tearful, disruptive, shouting, irritable, threats and shouting.

dementia. From this we established an observational engagement tool. Using this tool we determined which sensory activities create the most engagement.

Without doubt the most engaging activity is the Drumming session we provide in relation to understanding auditory perceptual changes in dementia. Drumming evokes an engagement response unseen in other activities. This finding is mirroring other research taking place across the UK and wider on effectiveness of drumming in mental health. However, we are not yet aware of any other organisation using drumming as a sensory tool for those with a dementia.

Case study Rose is partially deaf, non verbal, and inactive in her wheelchair. Rose was helped to use a hoop drum. The drum was held next to her chest so she could feel the vibrations. On feeling this, Rose made direct eye contact with the volunteer. When the drumming session was over and we were packing away, Rose got out of her chair and shuffled over to her helper. She took the helper's hand, looked direct into her eyes and then at the drum. Rose then made beating movements with her other hand.

Case Study John was born with Downs Syndrome and now has a dementia. Throughout the session John was smiling, laughing, singing and shouting Woohoo. At the end of each song he clapped loudly and shouted excitedly. Despite never having played a drum before John showed perfect rhythm. He did a solo performance to his favourite Abba song holding the drum close to his chest and resting his cheek on the hoop. When John finished, everyone cheered and clapped and hooted. John stood up and bowed several times to his audience. Tears were shed.

Feedback resulted in streamlining our initial activities programme into four main sensory workshops. This has helped condense our work to make evaluation more manageable. The Observational Analysis of activities linked to each of the primary senses is ongoing.

Thematic and Discourse Analysis of volunteer and carer diaries are in progress. Early findings suggest 'please come back' is the most often repeated discourse. Most often requested music is Abba, Queen and Elton John.

'You have given me back my rhythm - I thought it was long lost like my memory (wink)'

'Please come back'

'Made me feel I was worthwhile'

We have partnered with 36 different types of organisation/bodies

Tescos Isle of Wight
Tescos Fratton
Reshaping Newport
The Elms/Bembridge Community
You Trust
Age UK
Dementia Pathfinders
Parish Council
Southampton University
Making Connections CIC
Island Healthcare
Bodsters
Knit and Natter
IOW Dementia Partnership
Southampton Mental Health Partnership
Lilli
Happy Ponies
GP Surgeries
Residential and Care Homes
Memory Cafes
Alzheimer's Cafes
Bournemouth University
Global Rock Against Dementia
Purple Angels
Spring Arts Centre
Horticulture
One World Festival
Admiral Nurses
Isle of Wight College
Vectis Radio
People with dementia
Carers, family and friends
Activities Coordinators
Playlist for Life
Festival of the Mind

This does not include the number of individual groups such as residential homes or memory cafes

Partnership Working

We continue to strengthen partnership working by expanding our reach to more organisations and groups we can work with in equilibrium. We formed a partnership with seven other organisations for a tender for funding to the IOW CCG but were unsuccessful. However, we were successful in forming strong bonds with the other organisations during that process. We are involved in a similar process in Southampton. That partnership group obtained funding from the CCG to look at how we move forward.

Partnership Case Study Southampton

University asked us to deliver the TDS training programme to 175 first year student nurses who are working in hospitals in the localities we are covering. We found we could adapt the programme accordingly to accommodate larger numbers than usual. Bearing in mind working with people with dementia has always been considered the 'cinderella' of the nursing service, the feedback received was heartwarming. These students will be the future in nursing people with a dementia. As one student said (and her friends all agreed):

'I thought dementia was all doom and gloom - I didn't realise it could be so much fun. I want a future career working with people with dementia'

Partnership Case Study - As part of Dementia Awareness Week 2019, the Travelling Dementia Suitcase partnered with the charity Havenstreet Railway to take the lead in organising a day out on a steam train for people with a dementia and their carers. Six other organisations also attended to share their expertise and detail what they could offer. The event was attended by 52 people with dementia. Singing, laughing, smiles, sharing food, telling stories, networking and relaxing in the sun all helped to make the day a considered success. A brief evaluation of the day showed overwhelming hope it will be repeated.

Partnership Case Study – We partnered with the Spring Arts Centre in Havant to deliver our pop up dementia theatre and a drumming for dementia session. This resulted in networking and further contacts.

We continue to deliver the message about sensory deprivation in dementia to a wider audience through a partnership with Vectis Radio.

Volunteers

‘Understanding the importance of sensory activities has completely dissolved my perception of what dementia is all about’

All volunteers undertake 12 hours of training on on the why and how to deliver sensory activities. Participants gain certification and we are now providing a nationally accredited Leadership Award through Sports Leaders UK for those volunteers who find this beneficial for longer term ambitions..

We have been overwhelmed with volunteer support for several different reasons. First is the model of volunteer recruitment we are using i.e. involving carers and family members and secondly the activities are fun and engaging. Lastly, volunteers can see they are making a clear difference in the lives of someone with dementia. They report it makes them feel good.

We are learning there are different types of volunteers and each type needs a different level of support. Those volunteers who come to us because they are already working alongside people with dementia but want a better understanding of how to improve quality of life require little support. They move from novice to expert very quickly. As they integrate and then embed the Think Sense message in to their care, their need for ongoing support from us diminishes. This does have a knock on effect that they are less likely to produce reports.

There is another level of support required by those less experienced in understanding

dementia and newly diagnosed home carers. These volunteers require more support in helping them embody the Think Sense way of being .

‘This has given me something to do with my dad rather than just sit there thinking this will be me all too soon’

Another is the volunteer who is keen to work alongside our team helping us deliver at different venues. They are generally involved in delivery of our sessions working alongside staff.

Finally, there is the volunteer who wants to specialise in one activity based on their own unique skills. For example. one volunteer plays the harp..

Whilst we are delighted at the high level of interest in this programme, the challenge has been in trying to contain the rate and speed of take off. Hence, we trained 56 volunteers within the first six months of the project and then held back training any more so we could consolidate.

For us, it has been hard to let go of some of the volunteer relationships so early. The rapid novice to expert volunteers report having embedded Think Sense so much in to their caring they now can not see outside of that to keep reporting on what has changed. It seems once the paradigm shift took place Think Sense became normalised for those more experienced in dementia care.

Despite the challenges for us in collating data from them in terms of numbers and outcomes for people with dementia, we have every confidence that as our contact with those rapid novice to expert volunteers lessen, so the Think Sense message remains and is spread widely into communities.

Building Capacity

We are working towards accrediting and eventually rolling out a Travelling Dementia Suitcase social franchise on a national basis.

NATURE THERAPY CIC

CORE VALUES

We deliver heart centered work grounded in best possible evidence-based practice

We strive for innovation and creativity with kindness, fairness and integrity

We are catalysts for people to step into their own power whatever their circumstances

We Pay it Forward by supporting others within a culture of warmth

With this in mind, we are working with Creative Solutions to achieve that vision. They are helping us to evolve at an organisational level to prepare for this. One example has been in the creation of our organisational values.

An agreement by the Lottery to spread spend of capacity funding over the three year lifetime of the project will take into account the lessons we are learning. This includes lessons about the different frameworks we can use to deliver the Think Sense message and the subsequent direction of spread.

Lessons Learned

Delivery of the project has continually evolved and at the end of this first year we can finally sit back and explore the journey thus far. The grant has made it possible for us to try out different frameworks for delivery and to explore what works best in what circumstances. These Lessons Learned have been a vital part of steering our approach. From our lessons, we are able to inform others.

Our Advice to Others

Network, network network. Partnering is vital to success. We set up a sensory activities drop in café. People did come, but it was slow to get started and resource intensive compared to partnering with a facility already providing a service.

Have at least a six month run in to set up a project across different localities. Staged targetting of the three localities helped.

Make plans for how fast volunteers can move from novice to expert and the subsequent challenges in data collection. Be aware that paradigm shifts occur and once that happens, the practice you are trying to embed becomes normalised.

Volunteers all have different skills and experiences. Maximise the skills of individual volunteers

Try something new – you might never know the outcomes, We tried drumming with people with dementia and it has been an immense success.

Involve people with dementia at every stage, from interviews, to the training of volunteers, advising what worked for them and how we could improve

Gently challenge negative attitudes such as ‘don’t bother with her as she won’t join in’. Be the change you wish to see.

Do what you love and people will love what you do

Innovations

This project made it to the finals of the national nursing awards. This provided us with a UK wide audience to raise awareness of sensory deprivation. including Public Health Specialists nurses and allied health professionals.

We put the South of England on the global map by taking part in the World Rocks Against Dementia campaign.

We took part in Dementia Awareness Week by partnering with The Isle of Wight Steam Railway to provide a ride on a steam train through the beautiful and peaceful countryside.

Presentations on the project at four conferences in the South and one national conference. Presentation on Social Enterprise to budding entrepreneurs.

Dementia is the second most feared condition in the UK. Therefore we have adopted an ethos of non acceptance of negative comments and graphics of people with dementia. We do this by role modelling positive talk and images and gently challenging misconceptions.

We are piloting sensory innovations such as use of a Music of the Plants machine as part of our Touch workshop using Kokedama (Japanese string plants) and the use of cymatics creating visual displays of the sounds made on our drumming sessions.

Production of activity helpsheets for each of the five key senses for the social franchise package.

Way Forward

One of our concerns at the outset of the TDS project has been how to reach out to those people with dementia and their carers that are part of the 'hidden' community of care providers. Particular relevant for some rural and ethnic minority communities. Smaller communities tend to be more socially isolated and receive less support.

In september 2019 we will be trialling a **Compassionate Community** approach to raising awareness of sensory impairment and what can be done to negate harmful impact.

Our proposed model will include businesses, key institutions, local groups and the general public who will be invited to a local residential care home to take part in our activities programme. This will involve having fun taking part in the activities with the 48 residents. The dual aim is to reach those hidden with the Think Sense message and encourage volunteers to help with ongoing activities in the home.

The 3,688 people in the target community have one of the highest levels in the South of England reporting day to day activities are limited. Around 3.6 per cent reported providing 50 or more hours of unpaid care per week. This compares with 2.4per cent for England.

Lessons learned from this approach will help to determine if the TDS programme can be rolled out as a franchise via Parish Councils or other communities.

Finance

Please refer to separate financial report for full details of expenditure against the grant allocated.

A quick and dirty cost benefit calculation shows the cost per individual person with dementia in this project **is around £38 per person. This equates to £23 per person when carers are included.**

This does not take into account the wider cost benefits for volunteers, partner organisations and communities.

'I just absolutely love doing this thank you for letting me be part of it'

'Watching other people's pleasure and joy is infectious'

THE NEXT SIX MONTHS

Pop up Theatre, Demfest in Romsey

Rural Award nomination

Advisory group with those with early onset dementia through partnership with Alzheimer's Cafes

Pilot with local Drug Service to explore way forward for those with a substance induced dementia

Partnership with You Trust - training their carers to deliver sensory activities

Trade not Aid strategy to include franchise of TDS, sales, & delivery of additional training programmes

Inclusion of people with dementia in volunteer training package

Taking part in Rhythm to Recovery Drum Training in Belfast in June 2019

CPD Accreditation of Nature Therapy and Dementia Care volunteer training

Partnering with Universities and colleges to create a credible qualification for Activities Coordinators

Partnership with other charities to establish a digital loans system to share resources

Compassionate Community approach to establish wider reach to those less likely to seek support

Set up of sales section on our website to include our Dementia Care Activities Backpack

Use of Fit Bits in Drumming for Dementia sessions to explore physical changes i.e. health implications

