

A CASE STUDY IN WARM HUMANITY AND MEANINGFUL CO-PRODUCTION

THE ME MYSELF AND I CLUB

Briton Ferry





# 1

## THE ME, MYSELF AND I CLUB

### GROUNDED IN RESEARCH AND LOCAL NEED

*In 2012 a small group of people in Briton Ferry came together on a weekly basis to share a coffee, have a chat and support one and other on their journey of dementia.*

As the numbers attending grew the group facilitators, led by Anita Tomaszewski recognised that what started off as a small friendship club was slowly turning into a larger formal group and the that this club was addressing an unmet need in the local community.

Whilst in the early stages of developing the Me Myself and I club in Briton Ferry during 2013-14, Anita was a participant in a research project entitled Developing Evidence-Enriched Practice, which was funded by Joseph Rowntree Foundation and Welsh Government:

[www.jrf.org.uk/report/developing-evidence-enriched-practice-health-and-social-care-older-people](http://www.jrf.org.uk/report/developing-evidence-enriched-practice-health-and-social-care-older-people)

This was a collaborative action research project, which explored how older people, carers, social care practitioners and managers could use a range of research and other local evidence to respond to the Seven Challenges of the JRF programme A Better Life, which focused on what made 'a better life' for older people with high support needs:

[://www.jrf.org.uk/report/better-life-valuing-our-later-years](http://www.jrf.org.uk/report/better-life-valuing-our-later-years)

### THESE CHALLENGES WERE:

- *Promote a more positive image of old age – no them and us*
- *See the person behind the label or diagnosis*
- *Recognise that good support is founded in and reflects meaningful and rewarding relationships*
- *Enable the opportunity for older people to give as well as receive*
- *Share responsibility with older people (e.g. in making decisions and promoting collective well-being)*
- *Strengthen the individual and collective voice of older people*
- *Recognise that not just big innovative changes but also 'little things' can make a big difference.*





# THE ME, MYSELF AND I CLUB

In the Neath and Port Talbot project site, Anita, along with a group of older people, carers, social work practitioners and staff from Neath and Port Talbot Carers' Service worked together to address these challenges within the context of respite care, a service which they felt did not always nurture and support interdependent caring relationships. They felt that the fixed 'menu' of day care or residential respite care, aimed at separating carers from the people they support, could cause more harm than good. Neither did they create opportunities for older people and carers to give as well as receive or share responsibility with service commissioners and providers. The little things that meant a lot were also often missed. The following quotes illustrate the depth of feeling:



*"He just came out with it – out of the blue, "I will go into a care home, into respite for one week" – to give me a break and I was so upset about it. He hadn't mentioned anything about it to me, but he felt he was a burden on me. I couldn't answer. I said "why on earth did you say that?" He said, "Well you know it is too much for you". But it's not too much for me and it really upset me... it was awful"*

*"It's a huge problem... you have the group of people who can't come to a Carers event because the person they are caring for...mainly men..refuses to have anyone else look after them... we have people come together, but we in the Carers Service are funded for carers only and then social services are funded for service users or the carer and it is not really carers or family or holistic approach – it is one or the other... you are not looking at how they are affected as a family"*

*"I care for him and he cares for me... yes it is team work. You are a team"*

*"You can't have a positive outcome if you don't support them altogether"*

*"They suddenly have this label of a 'carer' and everybody forgets what they are actually capable of, who they are as people"*

Project participants decided to take a creative approach to exploring what meaningful short breaks might look like for them and did this through the medium of poetry with the support of Cheryl Beer, a creative artist. The result was the poem 'See me, not my shell' (reproduced on the last page of this booklet), which they also put to song.

As a result of their talking and learning together, two strands of work developed. Firstly, the exploration of links between social care and tourism, which included the development of links with Shared Care Scotland and secondly, how to develop relationship-centred short breaks in the local community that did not require the separation of carers from the people they support and also provided an opportunity for peer support. It is this second strand of work that the Me Myself and I Club took forward with great success.





## ESTABLISHING THE CLUB AND A RANGE OF ACTIVITIES

*In 2013 Me Myself & I (MMI) was formally registered as a Charitable Incorporated Organisation (CIO), and has gone from strength to strength.*

The club focuses on bringing about a sense of normality for people living with dementia and carers in their day to day life through a combination of non-stigmatising peer and volunteer support. The ethos of the club is to challenge negative stereotypes of people with dementia and the traditional service culture which does too, rather than with people. Member of the club also recognise a need for greater understanding about dementia in the local community and are committed to raising awareness and understanding of what it feels like to be living with dementia, and how other people can be helpful not hurtful.

The club has had to evolve rapidly over the last 3 years to meet the demand and growing need from partners, including ABMU Health Board and the local authority as well as referrals direct from the local community. As a result of growing interest and dementia, they have had to acquire a larger building and recruit extra volunteers. The club now meets in Parc Newydd, Briton Ferry and has over 20 volunteers that support over 40 people each week with an age range from 42 to 97.

Guests attend the Community Friendship Club either on a Tuesday or Wednesday afternoon. For many, the club is only chance they have in their week to leave their home, chat with friends, or continue their favourite hobby, be it a game of bingo, arts and crafts, shop in our clothes and gift shop, a game of table tennis or even football.

Over the past few years, the club leaders have discovered many local families who were at a loss and profoundly challenged by situations alien to them, that have come about as a result of dementia. Being able to share with and learn from other local people who have direct experience of people living with dementia has been profoundly helpful.





# “LIVING MY LIFE RATHER THAN ENDURING LIFE”

## A CASE STUDY

### THE PERSON'S BACKGROUND:

Mrs T lives in a remote part of Neath & Port Talbot aged 63 and lost her husband after being his care partner for many years. Following his death, she experienced a stroke which then resulted in her being diagnosed with vascular dementia. Mrs T found it hard at times to converse with people and often felt in low mood due to not only losing her husband but also struggling to come to terms with her own debilitating diagnosis of dementia.

She reluctantly joined the Me, Myself & I Club following the disbanding of a local meeting group she had attended following her diagnosis. Her reluctance stemmed from the fact that she felt anxious and socially isolated, living in a changing, unknown world of dementia.

At one point, she attended a 'knit and natter' meeting group as she had previously enjoyed knitting and crotchet, but on joining the group and anxiously introducing herself, openly saying she had dementia, the three ladies sat at her table got up and walked away leaving her sitting on her own.

### GETTING TO KNOW THE PERSON FURTHER:

We gently encouraged Mrs T to visit us at the club one afternoon about three years ago. We asked her, if she wouldn't mind telling us about the things that she used to like to do prior to her stroke and she told us how she used to love cooking, but was unable to remember how to do it anymore.

She also told us about her love of fashion and shopping, but how shopping had now become an anxious activity due to the many complexities of today's shopping experience. For example:

- Loud music being played in some shops meant she couldn't think properly
- Some shop assistants were not very helpful, saying *"if you can't see the size, it's not there or we don't have any!"*
- When she approached a till in other shops she was asked for a points card or a loyalty card, or does she want two bars of chocolate for the price of one and by this time she felt so confused and anxious she often left the shop without buying the items she had wanted.





## WHAT SUPPORT THE ME, MYSELF AND I CLUB PROVIDED AND WHAT DIFFERENCE IT MADE:

One of the members of the organisation is a keen cook and asked Mrs T if she would like to help her make some cakes. Mrs T was not very confident and a little reluctant, but said she would watch. However, over the weeks Mrs T confidence steadily grew and she started to make her own cakes with the hand-written recipes and notes the club member had given her.

Further cake making followed and one year on Mrs T cooks at the club or brings in weekly, the most beautiful cakes and or her speciality bread pudding which everyone clamours to eat. The pleasure is seen on her face when she tells people what she has made each week.

One other important facet of Mrs T regained cooking skills is that she is now also able to identify other guests who experience a similar lack of confidence as she once did and spends time helping other guests to take part in cooking and other activities.

Along with this activity Mrs T confidence has grown tenfold and due to her long-standing interest in fashion and shopping she now also manages the Me, Myself and I community recycling shop. She takes huge pleasure in sharing and matching clothing items for other guests to enjoy.

An added joy is that Mrs T is now so comfortable in herself, she has volunteered and become the group meeting spokesperson and ensures that each person's voice and views are heard around the weekly table meet.

Mrs T also takes part in the charity's Community Care Training and Volunteer Academy three-month programme of workshops on best practice in dementia care, where she speaks about 'how it can feel living with dementia'. These workshops are attended by people who are unemployed who also volunteer in the club, with the aim of securing employment as PA's in social care with families within the local community.

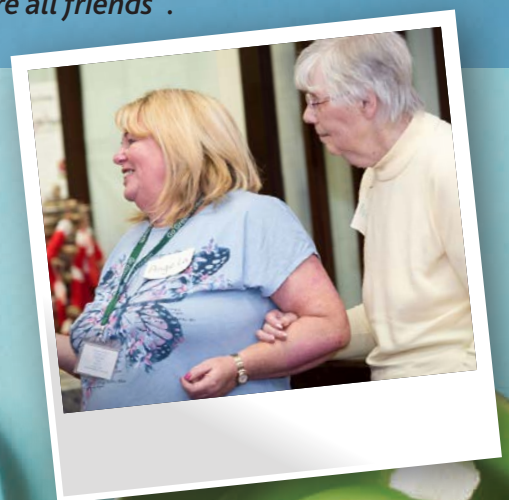
The 'icing on the cake' came three years on from first joining the club... Mrs T has now become engaged to be married to a fellow guest which has brought her a degree of happiness that she had never thought possible when given a diagnosis of dementia.

## OUTCOMES / MRS T:

- Has regained a sense of identity, recharged her self-confidence and now sees herself as person of value to others.
- Now has the courage to make bold decisions and has a sense of purpose in life
- Is no longer socially isolated and has become part of a community of people who work collaboratively 'driving forward' the Me Myself and I ethos of 'people helping people' which works to reduce stigma and discrimination
- Through her own empowerment has enabled herself and many other guests to see that 'life is for living rather than enduring'

## GUEST (MRS T) QUOTE:

*"I love this club as all my friends are here. I feel part of something special and it has given me a confidence I haven't had for a very long time. I greet new guests into the club and tell them don't worry you will enjoy it here as we are all friends".*





# THE ME, MYSELF AND I CLUB

Within the last 2 years the club has developed 3 other services; a Day Break Service, an Outreach Service and the Community Care Training & Volunteer Academy.

The Day Break Service is offered to people needing a full day break opportunity. As a result of the closure of 12 local authority day centres, the club is finding that referrals are coming through on a weekly basis.

The Outreach Service was founded as a result of a desperate case of a young women who was diagnosed with dementia at the age of 45. She was living in a most remote part of the Afan Valley with her partner who also had several health issues. Understandably, this couple were finding it difficult to cope with their situation. The club therefore provided an Outreach Companion, who was able to take the person out one afternoon per week, provide emotional support, promote her independence and confidence and provide much needed short break for her partner.



## DEVELOPING SOMETHING SPECIAL: THE COMMUNITY CARE TRAINING AND VOLUNTEER ACADEMY

*Older people and particularly those who are living with dementia are often seen as a burden, with nothing to give.*

The Me Myself and I club has turned this on its head, by creating an opportunity for local young and long term unemployed people, who may never have considered working in social care, to share in the life of the club and receive high quality dementia care training at the same time.

The Academy offers up to 12 weeks of training and 12 hours voluntary work for people considering employment in the care sector. Having developed excellent working relationships with the local Job Centre, Communities First Teams, other local projects and organisations, the club has successfully run 4 courses over the last 2 years and matched over 50% of people completing the course to Personal Assistant or Care Assistant roles within local care organisations.

This unique and reciprocal partnership between people with dementia and volunteer trainees brings benefit to all involved not least the people with dementia, who feel they are helping people to get on in life and develop a career.

Trainees learn first-hand about person centred care, including what dignity means in practice, how to build on people's strengths, and safeguarding. In addition to the training, the formation of caring and reciprocal relationships with members of the club through shared activities gives everyone a sense of meaning and purpose. In view of a national social care workforce recruitment crisis, the Academy is a beacon of hope and possibilities.





4

STRENGTHENING THE CLUB THROUGH DEMENTIA ACTIVISM AND LINKS WITH THE DEMENTIA ENGAGEMENT AND EMPOWERMENT PROJECT (DEEP)

The Dementia Engagement and Empowerment Project (DEEP) is a UK wide national network of groups for people with dementia.

All of the groups enable people living with dementia to have a voice and an opportunity be involved in shaping and influencing services and policies that affect their lives to varying degrees. There are over 90+ Groups in DEEP and the network is supported by Innovations in Dementia CIC.

Each group is independent deciding what they want to do and what their priorities are. Having a range of different groups means that the network may share, support, and learn from each other. Being part of something bigger makes everyone stronger. Groups say that DEEP is a place where they can be inspired and energised and can contribute to a growing movement. The groups are all unique and some meet in pubs on a social basis, other groups are based around activities and some are very formal.

The DEEP website www.dementiavoices.org.uk has many resource and guides created in consultation or by people living with dementia which are also an invaluable resource for professionals. You can also follow DEEP on twitter @DementiaVoices

The Me, Myself & I Club joined DEEP in the autumn of 2016, when Rachel Niblock the Co-ordinator of DEEP for Wales met with Anita and described what DEEP meant. Anita said that she felt reassured that what Me, Myself & I stood for was identical to the ethos of DEEP. She no longer feels that they are a lone voice in the wilderness.

The Me, Myself & I Club now host a DEEP Working Together grant to enable the communication and coordination of an increasing number of smaller groups joining the DEEP network across South Wales. They will ensure that no group feels alone and will be available to offer their own group as a source of advice, guidance and friendship as needed. They also host a number of DEEP Meet-Ups bringing together representatives from groups across Wales.

"I come here for the support, laughter and the kindness. Meeting me at the door with a smile. You cannot put a price on how much it makes a difference. Able to come here and do things together"

Me, Myself & I Guest

"Here I matter. What I think and say matters"

Member of the DEEP network

"Puts THE person with dementia at the centre and gives them a voice"

Me, Myself & I Guest

"So, a fun packed busy group today, we shared sad thoughts, profound thoughts and so much laughter. No one was judging us so we all felt easy sharing whatever we wanted to share with friends – just how people with dementia should feel – brilliant!!"

Wendy Mitchell

from Minds & Voices DEEP group





# 5

## THE ME, MYSELF AND I CLUB

### BECOMING MORE EFFECTIVE AS A SOCIAL ENTERPRISE WITH SUPPORT FROM THE WALES CO-OPERATIVE CENTRE

*In 2016, the club linked up with Care to Co-operate, a Welsh Government funded project hosted by Wales Co-operative Centre:*

[www.wales.coop/helping-people-set-up-care-co-operatives/](http://www.wales.coop/helping-people-set-up-care-co-operatives/)

The Wales Co-operative Centre's Care to Co-operate service has worked with the Me, Myself and I to:

- Support it to investigate co-operative approaches to growing its services, embracing inclusive ways of working with guests, volunteers and paid carers . As a result, the Me, Myself and I club worked closely with its guests to bring them into its new co-operative way of working.
- Help the charity formalise its communication processes with its guests in line with its amended business governing documents, and to further expand its co-operative working practices, building networks in its local communities and to reach further afield. The change means that guests, volunteers and its other wider community and corporate stakeholders, will be able to participate in future developments and decisions and have the power to vote on key decisions to take the charity forward.
- Support it to consider developing new co-operative partnerships. It played a key role in strengthening and gaining funding for the Community Care Training and Volunteer Academy. The new funding enabled volunteers to become employees and to run the Academy for more trainees on more regular basis. Many unemployed people have attended the Academy for specialist dementia training and then successfully secured volunteering, further education placements or employment in the care sector. The Academy has naturally developed a workforce of suitable Personal Assistants from the pool of people who have volunteered at the Me, Myself and I Club for its guests. A symbiotic relationship!

The Me, Myself and I Club has also accessed business development support from the Wales Co-operative Centre's Social Business Wales service. The service has worked with them to develop a business plan that sets out a clear three year vision and growth path for the charity. Social Business Wales provided assistance to develop and update policies guiding its environmental sustainability and equality and diversity.





## SEE ME, NOT MY SHELL

Life changes  
And you reach a point  
Where standing out is celebrated

Don't judge me  
Just love me  
It costs nothing to care  
Everybody has a voice  
They should have the choice  
To express when and where  
Diolch Yn Fawr

See me  
Not my shell  
See me  
Hear the stories that I tell

Build the new  
To fit us too  
And the things  
That we can still do

Who's going to do for me  
With dignity  
Expect equal respect  
In sharing the personal

It's the little things  
The wee little breaks  
The little things  
Is all it takes

It means a lot  
It makes a big difference  
The little things like  
Having my hair done  
The little things like  
Going to the shop  
A flexible plan  
Where I can  
Do the things that I can do

Yes, the little things  
Like a life of my own.

Come sooner  
Not too late  
Open doors and open eyes  
Older, yes  
But far more wise

Give me a break  
Within my world  
On my doorstep  
With my friends  
Not far away  
From all the things  
That are my life  
In my home  
Keep my life  
As my own

You have the children  
You have the family  
You build a home  
You work for life  
Don't take away the savings  
Of husband and wife  
We're giving back  
Learn to be part  
Of the wonderful world

Together is a mix  
Where old and young  
Fix things to together  
We're fish in the same water

Everyone needs a buddy  
A buddy to help and care  
Every house a castle  
My castle  
I'll stay there

Do we expect too much?  
Should we prepare for care?  
In case the time comes for me  
Should I share the responsibility?

We still need to drive  
Changing, changing buses  
Changing, changing lives  
It's a long, long walk  
When the carer's need caring  
See me as a person  
I'm a wife not a carer  
I'm a husband  
And I share with her  
My world

Always look on the bright side  
Have a bit of fun, I think  
Play the hand you're dealt  
Nudge nudge, wink wink

Don't charge me through the nose  
An older life knows and grows  
I can do things that you can't  
You can do things that I can't  
We all do what we can  
Now, that's a together plan

See me  
Not my shell  
See me  
Hear the stories that I tell

Poem written by older people, carers and social care practitioners in Neath and Port Talbot with support from Cheryl Beer as part of JRF Developing Evidence-Enriched Practice project work.

[www.jrf.org.uk/report/developing-evidence-enriched-practice-health-and-social-care-older-people](http://www.jrf.org.uk/report/developing-evidence-enriched-practice-health-and-social-care-older-people)





# THE ME, MYSELF AND I CLUB

*Briton Ferry*

FURTHER  
INFORMATION



Me Myself and I Club  
[www.me-myself-and-i-club.co.uk](http://www.me-myself-and-i-club.co.uk)

Wales School for  
Social Care Research

[www.walesscr.org](http://www.walesscr.org)

Wales Co-operative Centre

[www.wales.coop](http://www.wales.coop)