



# *Helping hand with Dementia Project'*

## **Section: 1 Background:**

The Helping Hand with Dementia Project was funded by Race Equality Foundation for three months. It began in August and ended in October 2020. Twelve families were selected, and they are responsible for looking after their loved ones living with Dementia.

### **Some of the issues identified were:**

1. 24/7 caring for loved one with Dementia
2. No form of respite
3. Isolation and loneliness
4. Financial stress

### **Aims:**

- Sessions for listening/counselling/stress management
- Guidance and use of relaxation therapies
- Assistance with debt management and relief

### **Objectives:**

- ✓ Give a listening ear to the struggles experienced due to the lockdown and other issues
- ✓ To provide counselling and stress management
- ✓ To help develop relaxation techniques to manage their stress.
- ✓ To support where possible with debt management or lack of funds. To aid better mental health outcomes.
- ✓ Give carers respite, by providing meals to the cared for.

### **Age range**

Carers is between 40 and 80 years. Cared for are aged between 70 and early 90's.

## **Section 2: Project delivery:**

The impact of Covid-19 lockdown on the health of BAME communities has raised great concern and Dementia has been highlighted as a major area for the elderly. Our charity has been listening to the experiences of our carers and were delighted to participate in this project.

Carers were contacted via telephone and were invited to participate in the project. They all agreed, and the initial assessment allowed us to deliver a person-centred and holistic

approach. We followed safe social distancing procedure whenever there was face to face contact.

Overall each family participated as much as their time allowed them to do so because as the saying goes, “life gets in the way” and we understood. Sessions were made flexible for all the participants.

<b>Intervention</b>	<b>Number</b>
Invitation telephone calls	20
initial assessments	11
Face to face contact and counselling sessions	16
Telephone counselling facilitated	1
Sign posting/ solution focused discussions	8
Financial assistance	
Home Cleaning	1
Travel cost	1
Hair products	1
Meals on wheels with flavour (4 families) cooked meals delivered to their homes	6
Individual wellbeing sessions	
jewellery making	2
hair maintenance	1
Telephone contact – approximately (weekly calls)	400
Home visits	5

### Section 3: Family

<b>Carer</b>	<b>Cares for</b>	<b>Employment status</b>
1. Diamond	Grandparent	Employed
2. Ruby	Parent and adult son	Employed
3. Sapphire	Lives out of Bristol and cares for parent	Unemployed
4. Pearl	Lives out of Bristol and cares for parent	Unemployed
5. Jade	Parent and has a neurological condition	Fulltime carer
6. Emerald	Spouse and parent-in-law	Employed
7. Crystal	Parent	Full time carer
8. Amber	Parent and siling	Employed
9. Jasper	Spouse	Retired
10. John	Spouse	Retired
11. Jack	Parent	Retired
12. Daniel	Parent	Full time carer

#### **Section 4: Counselling case studies will illustrate --**

- a) the impact of Covid-19 and the 'lockdown' on the lives of the clients,
- b) the anger and concern triggered by the realisation from the Black Lives Matter Protests of the deep-seated structural racism and inequalities that exists in society,
- c) the methods used to enable clients to gain awareness of their own needs and develop strategies for coping better with stress and isolation they experience during this challenging and unprecedented period.

#### **Case 1: Client A Joshua**

Joshua is a 60-year-old male who shares the caring responsibility for his mother with one sister. At the first meeting Joshua, was very reticent in his approach and wanted to talk about nothing else but the way in which he was discovering, through social media the impact of racism, worldwide. He found it difficult that his mother and sister could believe in a 'white religious system' that colluded in lying to Black people.

As a counsellor I believed it was important to give him the space to express his feelings, in a safe and non-judgemental capacity. By listening I learnt that he had experienced a lot of racism and low expectations throughout most of his school days, but there was one white teacher who recognised that he had potential and encouraged him to do his best. Through these discussions he began to accept that not all white people were intentionally racist but had grown up in a society which for centuries had portrayed black people as inferior.

Through further discussion he recognised how in many ways he himself had colluded with the negative stereotypes about black men in particular, and the impact of this on his life and that of his family. After further listening he explained that like many other Black males of his generation, he too had spent several years in prison. He was now out and finding it very difficult to get work of any real value. He believed that his anger and aggression led him prison. Further sessions with Joshua, revealed that he also had witnessed violence in his biological family. He talked about his father's experience of racism and the resulting behaviours towards the family. Joshua is estranged from some of his own children. He has a very good relationship with younger son who now lives with him. He is proud of his own children, who has worked hard to get themselves to university and secured well paid jobs. Through further discussion Joshua became aware of how his emotions can impact his physical health and mental well-being.

It appears that these sessions have given Joshua an understanding of his own behaviour and communication styles which are not always conducive to good relationships. Focusing back on the only white teacher who had gone out of his way to encourage himself, and other black children to do their best, he acknowledged that there are good and badly behaved people in all societies.

We discussed strategies for moving forwards:

We are now working together to understand and practice conflict resolution methods, listening skills and relaxation techniques. Since attending these one-to-one sessions Joshua feels he is better able, to listen and his relationship is improving with his sister, who is now more willing to support him with the care of their mother. He notes that this has a positive effect on his mother, who he dearly loves. Last week Joshua attended an interview for work, which he was successful at securing. Joshua feels that the session has seen him through a difficult time where he had felt alone.

### **Case 2: Client B - Ruth**

Ruth in her early 50's. She cares for her mother who is living with dementia and brother with serious mental health issues. Ruth explained that she had a very difficult relationship with her mother for many years since growing up as an adolescent. Since the father abandoned the family, she has felt responsible for supporting her mother who had been displaying mental poor health symptoms for many years. These grew worse resulting in the diagnosis of Dementia last year. Ruth also shares the responsibility for her mother with two other sisters and one brother, however, the bulk of the day to day care lies with her for several reasons -

1. Her mother lives at home with her and the brother. Her only daughter has recently left the family home as she finds the family tensions too much to cope with.
2. It is difficult for all her siblings to agree on the best way forward to care for their mother.

All these family tensions are now having its toll on Ruth, who is finding it difficult to sleep and concentrate. She expressed feelings of continuous exhaustion and of being stuck.

Further discussion with Ruth revealed that there was a communication problem between her siblings and herself which made it very difficult to reach a place where they could get together to find a positive way forward regarding the care of their mother.

During the discussion with Ruth opportunities arose which enabled her to focus on her own needs and her style of communicating with her siblings. Through this she recognised that she needed to find ways of supporting herself and taking better care of her own health. She decided that she needed to take some time to relax more, as well as finding a way of getting together with her siblings. By the end of the session she rang two of her siblings and one cousin to arrange a time when they could get together to plan a way forward for the good of their mother. She also realised that she was not responsible for everyone. Finally, she rang the organisation she works for and booked a week's holiday, something she had not done for two years. Ruth did however state that the daily meals provided for her mother were " a God send" " as it gives me something less to worry about."

### **Case 3: Coral -- Coral**

Coral is in her early 50's and has been looking after her 85-year-old mother for the past few years. Her mother was diagnosed with Dementia just before the onset of Covid-19 and 'lockdown,' in March. Coral is friendly and welcoming and came to the door wearing her mask. She looked sad and reticent. After a little hesitation I was allowed in. We sat in the large dining room at a social distance. She explained that it was difficult to leave her mother on her own. Her mother was very lonely and had been crying that morning as she feels everyone has abandoned her. This upsets Coral who then feels consumed with feelings of guilt and shame.

Coral is one of four siblings. However, due to Covid-19 lockdown, she is the only one her mother has seen, since June. The other siblings live outside Bristol. Two of the siblings' phone on a regular basis. There is very little contact with the brother. Coral was very open in talking about her diagnosis of bi-polar. Having bi-polar which meant that she had to give up a very responsible and well-paid job and come back to live in the family home.

She felt consumed with shame and embarrassment. She was lonely and longed for conversation. Coral said longed to be able to just meet with someone for friendship and chat. She said that most of her day was spent in her bedroom or with her mother, in her mother's bedroom. The only other activities they did together was, until recently take a daily bus trip into the shopping centre. But this was at her mother's request and that she was finding it

exhausting. As it she was having to do it seven days a week, it also meant that they were having to get two buses to and from town. Coral stated that after speaking to the co-ordinator of the project, she was given several solutions to resolve this situation. The first of which was to suggest taking her mother for a walk locally. Coral stated that this solution worked. Before Lockdown they were regular attendees of the local church, due to Covid19 they had lost all contact with the other church members, many of whom were elderly and in a vulnerable situation regarding their health. Coral and I also talked together about possible activities she could do as well as things they could do together.

Suggestions of things she could attempt to do to develop some interests:

Taking up a hobby, listening to music with her mother, reading the bible with her mother (as her mother still did this regularly), dancing with her mother, ringing friends and enquiring about them, reaching out to her neighbours, doing weekly online yoga practice as well as Movement for healing sessions with me.

Coral informed me that her sister had also tried to encourage her to do similar things. Her sister makes and sells jewellery. Coral had a bead making jewellery kit in the house that she had never used. I asked if she would like me to start doing some with her on my next visit.

On the following visit Coral informed me that she had phoned several old friends and people from her church. They were pleased she had made contact and wanted to keep the communication going. The priest from the local church also rang her and enquired about her mother.

We started the bead work together and she produced a lovely pair of earrings. Her mother came downstairs, we played some music and danced to Bob Marley. Her mother also began to talk about her early experience of racism which she endured at work when she first came her. She remembers the humiliation and shame she felt because of it. As a result, she went to work in a hospital where she later injured her back. By the time the session ended both carer and mother looked and sounded much happier and said they were looking forward to the next session. Coral and her mother also receive, daily meals from the Project.

#### **Case 4: Client D -- Moses**

Moses 70-year-old has been living with the effects of a head injury which happened at work in 1973. He is the only carer for his 87-year-old mother and his own health condition has limited him in how much he can now do outside and inside the home. He was concerned that his mother was refusing to eat and is grateful for the meals provided by the Project which has cause her to start eating again. He talked about his loneliness and isolation because he is alone in the house with his mother.

Moses explained about his reluctance to visit or have friends visits because on the sad situation, a close friend had found himself in. It appears that this friend had been infected with Covid-19 and was unaware of it, eventually three other people were infected. Unfortunately, one of them was the friend's father and he died from Covid-19. Moses explained that his friend now must live with this on him conscious. He was fearful that he could be in the same situation with his mother if he were, to contact this potentially deadly virus. Joshua was thankful to have a space to talk about his own needs and fears around Covid-19.

In the end Moses agreed that he would get some music to play in the home as his mother use to enjoy listening to gospel music. He also felt let down by the people from his church so had stopped listening to the Christian radio or TV channels. However, he agreed to get

some gospel music to play for his mother. Moses has however agreed to meet weekly to see how things develop.

### **Section 5: General themes identified --**

- All the participants felt more isolated due to the impact of Covid-19.
- Many felt that before the 'lockdown' they were already experiencing feelings of isolation, loneliness, and financial worry.
- Several talked about the sadness and pain they felt for the 'loss' of their parent whom they felt they were unable to 'make better.'
- They talked about shame, which has led to self-imposed isolation on the part of the parent or partner who realised that they were not as strong or capable as they use to be.
- Some identified that they were unable to sleep during the day and was now experiencing levels of anxiety and depression.

### **Section 6: Feelings expressed/feedback**

Feeling of isolation and loneliness, tension, conflicts between family members and vicarious trauma, were all heightened during lockdown.

In addition, to all these factors, carers experienced more fear and worry due to the recorded high numbers of Covid-19 related deaths in the BAME communities and the elderly population in nursing care homes.

Further concerns and feelings of insecurity and anger were exacerbated by the Black Lives Matters protests, which raised issues of racism and discrimination and inequality. For some, issues raised by Black Lives Matters (BLM) protest around the world reminded many like Joshua, of their own experiences of living with racism and the impact of this on their lives.

However, the service users were pleased that at last BLM protest has raised the veil to give a voice to uncover the deep inequalities and unconscious racism in society. In other words, on the one hand there is relief that at last society recognised the deep inequalities experienced, on the other hand those painful wounds were triggered again. This created confusion, anger, sadness and feeling of inadequacy.

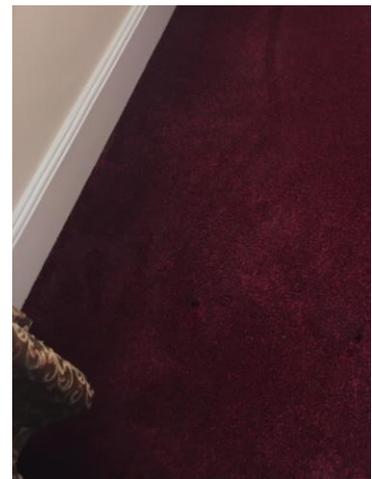
Underlying all these issues were feelings of being left to fend for themselves or of being left alone, during lockdown. The service users stated that the opportunity to explore these feelings in such a time was highly appreciated. Also, the lockdown has shown the true value and importance of connection and community which they felt the project is offering to them and their loved ones. A safe space to express their emotions safely and without judgements.

The project has officially closed but work will continue with the participants as they have requested to remain with the programme. Some have said that we should be expanding the programme to the wider community because they believe there are other who need the help but do not know where to go or that a programme like this one can help them through the hurdles.

We called a pilot because our hope and vision are to replicated the positive lessons and outcomes to the wider community.

# SUPPORT WITH CLEANING THE HOME

## BEFORE AND AFTER



# RELAXATION THERAPY – JEWELLERY MAKING



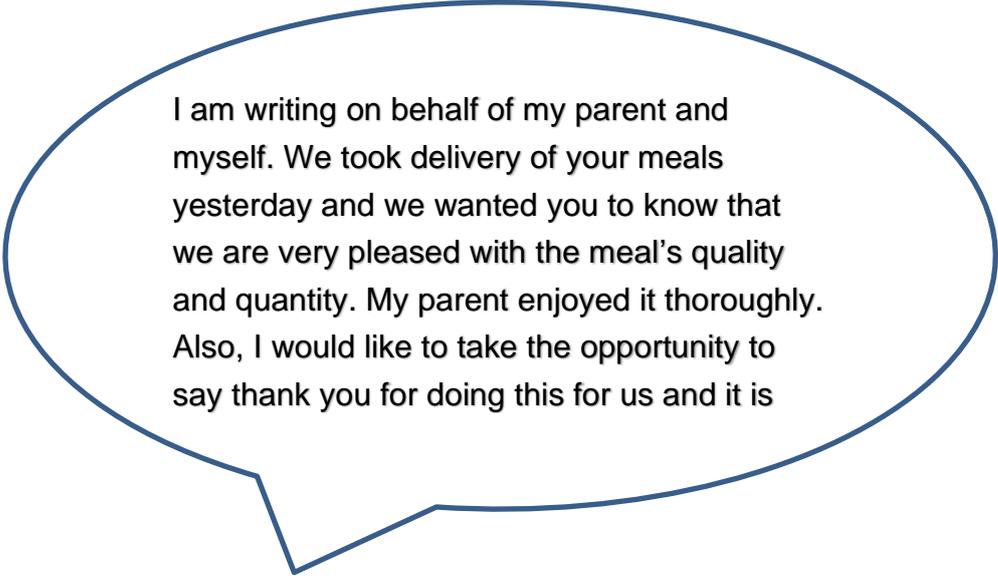
## MEALS ON WHEELS WITH FLAVOUR



## RELAXATION AND BEAUTY



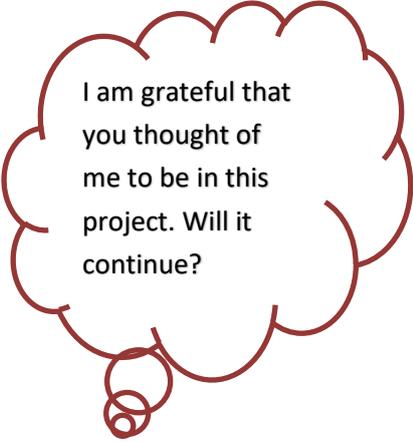
## FEEDBACK



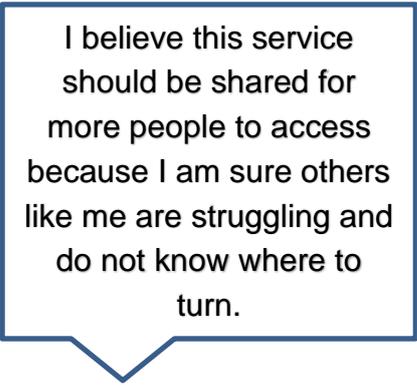
I am writing on behalf of my parent and myself. We took delivery of your meals yesterday and we wanted you to know that we are very pleased with the meal's quality and quantity. My parent enjoyed it thoroughly. Also, I would like to take the opportunity to say thank you for doing this for us and it is



Thanks for offering me the opportunity to talk and look after me.



I am grateful that you thought of me to be in this project. Will it continue?



I believe this service should be shared for more people to access because I am sure others like me are struggling and do not know where to turn.