

# Appendix III – Focus Group Findings

Between 18<sup>th</sup> July 2023 - 9<sup>th</sup> August 2023 4 focus groups were carried out across Reading to gather the views and experiences of adult carers across the borough. These focus groups ran alongside surveys which ran from 5<sup>th</sup> June -31<sup>st</sup> July 2023, available for both adult and young carers in Reading.

The findings from both surveys and these focus groups have informed the development of the Joint All Age Carers' Strategy and Action Plan for Reading, which will launch in July 2024.

Please find within this document the notes and findings from each focus group.

## Focus Group 1

**Age UK Reading Dementia Carers Support Group - Unpaid Carers Focus Group**

**Date: Tuesday 18<sup>th</sup> July 2023**

**Number of Participants Engaged: 14**

1x facilitator from RBC

1x facilitator from Age UK Reading

Main themes:

- External input to help self-identify as a carer
- Utilising local health services to maintain wellbeing, such as the memory clinic
- Need for clear and accessible information to help carers understand their rights and entitlements
- Being able to access grants for home improvement through supportive care assessments
- Time constraints and lack of bespoke care/specialised care impacts on ability to engage in other activities
- Expressed interest in having places/activities for both carer and cared for and the need to build a support network via an information hub
- Transport to get to places and activities is an issue

**How did you first realise you were a carer?**

- Self recognised
- Alzheimer's Society
- Age UK
- Attending a memory clinic course for the cared for person who was diagnosed October 2020

**What is most important to you to maintain your own wellbeing?**

- Counselling - participant had counselling through the memory clinic during Covid but now pays for private counselling
- Carer burnout/exhaustion/stress/tiredness means you have to make decisions around your own health as a carer but this can be difficult
- Understanding rights and processes to avoid the stress of having to navigate unclear systems

### **What has been the most valuable support you have received as a carer and why?**

- DF grant - meant a stairlift was put in, but it felt like it was a case of the right person at the right time
- The last OT was supportive and made it possible to get a standing lift/chair and suitable equipment to help with day to day

### **Is there currently any support/groups or activities you would like to access But are not currently available?**

- It's too difficult to get care for your cared for person to be able to attend anything like a support group etc. For one participant their cared for person requires 2 carers and this makes it even harder to have any time away.
- It would be good to have nicer environments to meet with loved ones/cared for person involved
- An information hub would be very useful and would help to build up a support network
- Transport is a challenge, there is no entitlement for carers and hospital transport is difficult. Over 65s are not entitled to motability which means if your cared for person is over 65 you do not get any support with transporting them as the carer. There are volunteer drivers in Pangbourne where it's pay what you can and this runs well

### **Additional themes/topics**

#### **Suggestions for what could help unpaid carers in Reading:**

- A checklist of basic information that might be needed on your carer journey
- An information hub to help build up a network of support
- Transport support (volunteer driver scheme in Pangbourne was used as an example)
- An understanding of escalation routes in the system, for both adult social care and health
- The carers 'grant' process needs to be clearer and more transparent
- Communication around the process for applying for respite needs to be clearer and more timely when you *do* apply
- An advocacy scheme for carers was strongly requested by the group - many feel that going into situations where decisions need to be made or when you need to understand a lot of information this can be challenging. There isn't always clear information to take away to fully understand what has been discussed and it is not always clear what carers are agreeing to or what their rights are in a conversation.
- Regular respite, for example a morning a week being available and not means tested
- Financial support
- Care being available so that carers can attend support groups
- Support with blue badge applications
- Honesty and transparency from adult social care around processes, entitlement and wait times

#### **Challenges experienced by carers in the group**

- Carers guilt - one participant talked about reaching crisis point and feeling unable to carry on caring for their cared for person
- Knowing what the future holds is very distressing, all the unknowns cause stress. This includes unknowns about the future for their cared for person, but

all of the unknowns created by the system in terms of what support is available, when and for who

- Transport is a challenge
- Access to care and respite
- There was strong mistrust of services expressed by most of the group, particularly mistrust of the NHS, Adult Social Care and Thames Valley Police
- One participant talked about the assumptions made about carers from particular cultures and ethnic backgrounds, there is a perception that the extended family will pick up the support for the cared for person.
- One participant also felt there is an underrepresentation of ethnically diverse families - at support groups but also in general around communications/ cultural understanding from officers supporting carers/cared for
- There was no local messaging or comms to carers about PPE during Covid and this was a struggle which meant carers were trying to source their own PPE during the pandemic, when they were actually entitled to PPE from the government. This was not communicated and was frustrating as a carer
- There should be a 6 week timeline from the assessment for a carers grant to receiving a grant, a number of participants had experienced more than 12 months having to wait for this support. This has had a knock on effect to when carers can receive their carers grant and has resulted in a number of participants in the group only receiving a carers grant every other year when they should be able to access this support on an annual basis.
- There are real challenges in understanding escalation routes within adult social care particularly. One participant gave an example of having a negative experience with adult social care, waiting for more than one year for the personal budget to be processed. The participant was regularly contacting adult social care by email and telephone but never received a response and so they contacted their local MP and once the MP was involved the process moved quickly. The participant felt it shouldn't be that difficult and raised concerns for carers who may not have the education level/time/health/capacity to fight for support or navigate the system in this way.
- One participant had recently had a difficult experience with an OT home visit. The participant felt like the purpose of the visit was not communicated, there was an understanding that the OT was attending to assess the cared for person and understand what equipment could support, but the OT started doing a financial assessment. The carer felt that the OT was very judgemental and that the visit was very intrusive, underhand and felt very anxious and uneasy for a number of days after the visit as a result of this. If the purpose of the visit was communicated from the beginning this would have been a less stressful experience.
- There are challenges with the incontinence clinic - you only received the pads themselves rather than the pants they sit within. You often don't receive enough pads at a time and often you have to purchase your own, but this is very costly.
- One participant expressed some distress over a recent experience of their cared for person returning home from hospital, the hospital would not discharge the cared for person without the carer agreeing to a live in carer and paying for this herself. The participant didn't seem to understand this process or why this decision had been made and wasn't sure whether they had any say in this decision.
- One participant shared their story of making initial contact with adult social care when they started needing to care for their cared for person but found the whole process of applying for support too stressful and in the end gave up full time work and now works 8 hours a week but otherwise is a full time carer for

their parent. This participant does not receive any support, financial or otherwise from any authority and has serious apprehension about applying for any support again.

- Many participants felt like adult social care is very unapproachable and makes it as difficult as possible to receive any support. Many participants talked about feeling like giving up and reaching crisis points themselves many times.
- There was a feeling that you needed to understand how to play the system to actually receive any support, even if it's support you are legally entitled to.
- You need time, knowledge and persistence to get the support you are entitled to

### **Positive experiences**

- Almost all of the positive experiences shared were around receiving equipment like stairlifts and standing chairs after having a supportive and good OT
- Two participants also spoke about receiving a phone call from someone at adult social care to check in on their wellbeing as a carer - they were not able to recall who this was or whether they were given any specific reason for receiving these calls. (Assumption this might be welfare checks/an outcome from weather alerts being raised or during covid.)

## Focus Group 2

### **Alliance for Cohesion and Racial Equality (ACRE) Unpaid Carer Focus Group**

**Date:** Tuesday 25<sup>th</sup> July 2023 11.30am-1pm

**Number of participants engaged:** 16

X1 facilitator from RBC

X1 facilitator from ACRE (who also provided translation support)

### **Overall Findings**

#### **Main Themes:**

- Challenges around recognising the role of an unpaid carer outside of what is naturally expected within the culture
- Stigma and shame around accessing support (especially financial support) as a carer
- Stigma around diagnosis and the need of the cared for person
- Lack of understanding of what support is available and how and where to access it
- Barriers to access support include language barriers, digital access, a shared experience or understanding with those delivering services/support
- Schools, GPs and religious and grassroots communities are the gateway

#### **What do you think of as an unpaid carer? What does this term mean to you, if anything?**

- This is a different concept in our culture, it is expected that you will care for your parents/family/children/community as part of your job and you shouldn't be paid or receive anything for this. It is your duty.
- There is a lot of shame around getting support or accessing financial support around something you are seen as expected to take on as a duty of care. There is shame in the Muslim culture around being paid/claiming financial support to care for your family member.
- People don't want to have this label through the fear of their cared for person being labelled/stigmatised, for example people might avoid getting a

diagnosis for their cared for person because of the shame or fear of being stigmatised and this then means support is not available for either the cared for or the carer. 'People need to be shown that it is better to get help than to suffer in silence.'

- A number of participants were parent carers, caring for children with SEND and talked about how they see their caring role just as part of their parental responsibility and didn't necessarily know you could access support as a carer.
- Participants talked about how some of these cultural barriers around recognising yourself as an unpaid carer means people do not access any support
- One participant shared their story of realising their role as a carer and finally receiving some support and shared a feeling of being lighter/recognised
- A lack of information as to what support is available was also mentioned as a big barrier for people who already have the cultural barrier around feeling shame or accepting support for their caring role. Unrecognised carers aren't aware of the support available to them, in addition to the stigma from within their community, this means these carers do not reach out for support and do not understand what they are entitled to.
- There was also a noted lack of information as to what support is available outside of financial support, so where there is shame around receiving financial payment for their caring role there was no understanding that there might be other types of support available.
- Language was mentioned as a barrier.
- Schools, GPs and grassroots community support are the key to getting over the cultural barriers.
- Many participants mentioned that they would look to religion for support for example, preferring to go to their pastor/priest/imam for anointment.
- Often people are signposted to look online for support but there is a digital barrier meaning people do not follow this up or are unable to follow this up but will not share this challenge with the person/people signposting them.
- It would be good to understand your entitlements/role from a GP, maybe with a GP letter to be able to access support.
- Some participants spoke about the care they provide to family members back home - this was talked about in terms of emotional and financial support that is given but that this also takes a big toll on the emotions of the carer.
- There is a fear around no shared experience with those providing services and this puts individuals off from then accessing those support services.

**If you found yourself in a position of caring for someone and you needed support, where would you go?**

- Pastor/priest/religious leader - but this can be comforting or stigmatising, depending on the leader as some may see a child with SEND as demonised for example, your whole family is then demonised.
- Religion is the first port of call.
- Supportive religious leaders help with prayer and healing and provide spiritual comfort.
- Going to a community forum is helpful and considered a safe space, this is true for the Community Wellbeing Hub too.
- Finding a safe space can be challenging initially, especially moving from home where there is the expectation of 'a village raises a child', moving here where you then lack a support system is hard.
- Many participants said they would go somewhere they could express their emotions in their mothertongue. Translation and interpretation is key.

- Through Covid, communities were able to come together and form support networks, we could use these links to promote the help that is on offer
- Churches/Mosques - talks with Imam on a Friday
- To the Community Wellbeing Hub (ACRE) for Talking Therapy workshops with James, for example the Stress Less workshops and the 'Drumming Down your Stress' workshop.

## Focus Group 3

### **Coley Park Over 50s Club Unpaid Carers Focus Group**

**Tuesday 1<sup>st</sup> August 2023 10.15am**

**Number of participants engaged: 12**

1x RBC Facilitator

### **Overall Findings**

#### **Main themes**

- Caring role is like a full-time role but without the same recognition
- Lack of awareness of wider community and voluntary sector services to contact for further support
- Self-identification is not intuitive as carer sees their role as a continuity of their relationship with the cared for
- Caring role brings satisfaction and serenity in knowing you've done what you could
- Being physically healthy is a contributing factor to wellbeing
- Having provision in place for respite care and breaks allows carers to engage in other activities and have a rest
- Utilising local infrastructures for activities and support groups
- Support to get to attend carers group activities such as a transport service

#### **What do you think of when I say unpaid carer?**

- It sounds like someone that is looking after family
- One lady said that it sounds like her life as she looks after her 60-year-old daughter 24/7
- Sounds like a lack of recognition as you don't have access to anything, and you do the same job people get paid to do

#### **If you found yourself in a position of caring for someone and you needed support where would you go?**

- Nobody knew who they would go through to (so a breakdown of services was given)
- They don't go through the GP or Voluntary Sector and just go to Adult Social Care for any issues

#### **How did you first realise you were a carer?**

- One person attended a voluntary sector organisation and was told she was classified as a carer
- None of the others could identify when, some said they wouldn't have called themselves one until I mentioned the definition at the beginning of the meeting and would have just thought of themselves as a family member to someone with needs.

**What is most important to you to maintain your own wellbeing?**

- Being physically healthy
- Satisfaction of supporting their family
- Having no regrets when the person they care for passes away

**What has been the most valuable support you have received as a carer and why?**

- Access to respite in a Care Home (2 weeks for mother) as it helped to have a long break
- Regular Day Centre sessions as that's why one person could attend this community centre group

**Is there any support/groups or activities you would like to access but are not currently available?**

- Transport to and from support groups for the carer as they're currently reliant on family
- They want the Community Centre better utilised as they don't want to go to other venues
- Participants were not aware of any other services they might want so didn't provide any other feedback

## Focus Group 4

**Whitley Wood Community Centre Over 50s Lunch Club Unpaid Carers Focus Group**

**Wednesday 9<sup>th</sup> August 2023 11am -12.30pm**

**Number of participants engaged: 2**

X1 RBC facilitator

**What do you think of when I say unpaid carer?**

Topic: Carer identification/recognition/understanding of a caring role

Response:

- An unpaid carer is someone that provides support with personal care, washing, shopping, housework, attending GP appointments, hospital appointments, making sure medication don't run out.
- My experience of the 6-week reablement service was very stressful. The paid carers didn't want to wear shoe covers when entering the house.
- Not being fully supported by family members and all the care responsibilities falling on one person only.

**If you found yourself in a position of caring for someone and you needed support, where would you go?**

Topic: Understanding existing support networks/routes for support & information/understanding knowledge of support and how to access it

Response:

- Spending time with my grandchildren - but I don't get enough time to do that.
- Spiritual family supporting and engaging in spiritual activities
- Checking online for support services

- Contacting social services for the cared for - but sometimes not very helpful experience

### **How did you first realise you were a carer?**

Topic: Carer identification/recognition of role across the system

Response:

- We knew from day 1

### **What is most important to you to maintain your own wellbeing?**

Topic: Carer wellbeing activity/understanding existing positive support

Response:

- Regular and ongoing support
- Respite care
- Family taking on more responsibilities to support and alleviate so as to avoid breaking point
- Willingness from family members to support
- Spa / Time out - at least once a month
- Spiritual activities
- I have not had a break at all within the last 2 ½ years
- Original offer of support from family members didn't materialise - this adds pressure as can't switch off
- The caring role tends to fall to one sibling with support sometimes from another - no matter how many siblings there are
- Need to warn new carers that that reality if caring falls to one person in the family - manage expectations realistically
- Unpaid carers need to not turn down help when offered

### **What has been the most valuable support you have received as a carer and why?**

Topic: Understanding positive support available e.g. TEC/ respite/ sitting service/personal assistants/family & friend/support groups etc.

Response:

- Talking to someone or a service that knows what is available and using the Reading Services Guide - that was invaluable - felt like a load was taken off my shoulders.
- Knowing about this lunch club was through the Reading Services Guide
- Word of mouth, a carer attending because of knowing another carer attending the lunch club

### **Is there any support/groups or activities you would like to access but are not currently available?**

Topic: Understanding gaps in support infrastructures/wellbeing activities to support carers

Response:

- Day care service with professional carers
- Transport from and to home provided
- Sitting service
- Respite care
- Having peace of mind to go into town and meet up with friends
- Planning ahead for family support

Additional comments:



- One carer didn't have a carer's assessment done
- Wokingham looks after their carers better than Reading - for example, the home from hospital service in Wokingham is much better. AUB provides the home from hospital service in Wokingham and gets phone calls from Reading residents.
- The service is Reading commissioned to British Red Cross appears not be of good standard
- Unpaid carers need access to information about where to find incontinence pads and how to order them, how to order catheter pads and diabetes injection needles for example
- Support needed to understand the nature of ailments described in a GP/Hospital diagnosis letter
- Timing of professional carers visiting the cared for - long gap sometimes between the lunch slot 1pm and the dinner slot 7pm or bed time slot too early at 6pm