

Loneliness and social isolation: What role can Meeting Centres for people affected by dementia in the United Kingdom play?

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Loneliness and social isolation: What role can Meeting Centres for people affected by dementia in the United Kingdom play?

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3 **Loneliness and social isolation: What role can Meeting Centres for people affected by dementia in**
4 **the United Kingdom play?**
5

6 **Abstract**
7

8 Purpose: Loneliness and social isolation are known issues for older people, particularly those living
9 with dementia. As evidence-based social clubs helping people affected by dementia adjust to the
10 changes that a diagnosis of dementia brings, Meeting Centres have the potential to reduce
11 loneliness and social isolation.
12

13 Approach: Between May 2019 and December 2023, 29 Meeting Centres participated in data
14 collection activities capturing demographics of members and carers. Loneliness data captured at six-
15 month intervals were analysed using paired t-tests.
16

17 Findings: Over 1020 members and nearly 700 carers were supported by the 29 Meeting Centres.
18 Attending a Meeting Centre had a positive impact on reducing loneliness and social isolation for
19 members, with female members most likely to experience benefits. Similar benefits were not seen
20 for carers, likely due to less participation in activities. While Meeting Centres play an important role
21 in addressing loneliness and social isolation, greater impact may be possible by increasing their
22 appeal to men and younger members, and encouraging active engagement and participation from
23 carers, particularly those who are male and/or older.
24

25 Originally: The Meeting Centre network is ever-expanding with around 70 Meeting Centres
26 operating across the UK. This study is the first to bring together data from those Meeting Centres
27 engaging with data collection.
28

29 **Key words**
30

31 Social isolation, loneliness, dementia, community support, Meeting Centre, active engagement
32

33 **Introduction**
34

35 Loneliness (lacking companionship or good quality relationships) and social isolation (having fewer
36 social contacts) are global issues for ageing populations which can negatively impact older people's
37 physical and mental health and their quality of life (Luanaigh & Lawlor, 2008; Landeiro *et al.*, 2017;
38 Chawla *et al.*, 2021). They are acknowledged as risk factors for all-cause morbidity and mortality,
39 comparable to smoking, obesity, alcohol consumption and physical inactivity (Landeiro *et al.*, 2017;
40 Chawla *et al.*, 2021).
41

42 Loneliness and social isolation are also significant issues for people living with dementia and their
43 family carers. Around a third of people with mild-to-moderate dementia experience loneliness, while
44 70% of people with dementia stop doing activities because of a lack of confidence, 68% worry about
45 becoming confused, and 60% worry about getting lost (Alzheimer's Society, 2013; Victor *et al.*,
46 2020). Additionally, 62% of family carers experience loneliness (Victor *et al.*, 2021). With around
47 982,000 people in the UK living with dementia (Alzheimer's Society, 2024) and around 700,000
48 people in the UK providing informal, unpaid care for someone with dementia, loneliness and social
49 isolation represent a significant issue for people affected by dementia (National Institute for Health
50 and Care Research, 2020; Victor *et al.*, 2021).
51

52 Services aimed at reducing loneliness and social isolation fall into three main categories: one-to-one
53 interventions; group services; and wider community engagement (Social Care Institute for
54 Excellence, 2012). Group services – particularly those with a 'creative, therapeutic or discussion-
55 based focus' – are among the most promising. The National Institute for Health and Care Excellence
56

(2015) promotes the use of activities as a way of encouraging social interaction, including the role of group-based activities. Its guidance suggests 'multicomponent activities' combining aspects such as singing, arts and crafts, physical activity, intergenerational activity, and activities relating to hobbies and interests as well as other learning opportunities.

As an evidence-based group-based community initiative (Brooker *et al.*, 2018), Meeting Centres (MCs) are ideally placed to combat loneliness and social isolation for people affected by dementia. There are around 70 MCs in the UK, with an underpinning ethos of supporting people affected by dementia to adjust to the changes that a dementia diagnosis can bring. This 'adjusting to change' model (Brooker *et al.*, 2017) focuses on providing practical, emotional and social support to people living with mild-to-moderate dementia and their family carers. MCs aim to: promote a positive self-image building on what people can still do; offer support to both the person living with dementia (member) and their family carer, friend or supporter (carer); promote social contacts; and offer a programme of activities including physical, cognitive, (re)creative and social activities (redacted for review).

Aim

This article aims to explore what data collected by MCs tells us about their impact on loneliness and social isolation.

Methods

Data collection

As part of regular data collection activities, MCs are asked to record anonymised attendance data and basic demographics about members and carers. To measure the impact of attending an MC members and carers are invited to complete short evaluation booklets when they are new to an MC (baseline) and repeated approximately every six months (follow-up). Within the booklet is the Three-Item UCLA Loneliness Scale (Hughes *et al.*, 2004) with the additional 'direct measure of loneliness' question (Office for National Statistics, 2018).

Completion of the booklets is voluntary and does not affect the ability to attend an MC. Members and carers are provided with an information sheet about the data collection and are required to provide informed consent. For members without capacity, a family carer can act as a consultee and provide consent on their behalf. Favourable ethical opinion was granted by the relevant ethics committee at the authors' university.

Analysis

Each UCLA question is scored on a scale of 1 to 3, combining to provide an overall score between 3 and 9. A response is required for all three questions to get a valid score. Higher scores indicate greater loneliness, in particular relating to lacking companionship, feeling left out and feeling isolated. The additional loneliness question is scored on a scale of 1 to 5, with higher scores indicating greater loneliness.

Scores were analysed at four time points: baseline; up to 6 months later; up to 12 months later; and longer-term. Members and carers were included in the analysis if they had a valid score at baseline and at least one subsequent time point. Mean scores were calculated at each time point, with paired samples t-tests performed to evaluate possible differences between the scores at baseline and each of the other time points. The paired t-tests only included people with a valid score at both time points being analysed.

To explore possible differences for sub-groups of members and carers, independent sample t-tests were carried out at each time point. For members, the sub-groups were males/females, and younger/older (75 and over) members. For carers, the same sub-groups were considered, with the addition of the relationship to the member, classed as a partner or spouse, or other relation. Due to relatively small sub-group sizes, particularly for carers, analysis was minimal but was conducted at all time points for completeness.

The demographics were analysed using descriptive statistics to get an overall picture of who MCs support.

Findings

Between May 2019 and December 2023, 29 MCs engaged with data collection activities, and findings are based on data available by the end of January 2024.

Overall, 1023 members and 691 carers were supported by the 29 MCs (Table I). Where sex is known, members are split evenly at 49.2% male and 50.8% female, while carers are more likely to be female (72.1%). Members are likely to be older than carers when they join an MC, with 74.0% of members being aged 75 or over compared to 40.4% of carers. Carers are more likely to be a spouse or partner of the member (59.9%) than another relation (40.1%).

< Insert Table I about here >

Findings for MC Members

Of the 1023 members, 211 had a valid baseline score for at least one loneliness measure. Sixty-five members also had a valid score for at least one follow-up time point. Where known, members included in the analysis were more likely to be male than in the wider MC population (58.3% compared to 49.2%), but age wise were similar to the wider MC population (72.2% aged 75 or more compared to 74.0%) (Table I). The mean loneliness scores showed a reduction (improvement) over time for both measures (Table II).

< Insert Table II about here >

There was a significant difference between the UCLA scores at baseline ($M=5.68$; $SD=2.28$) and in the longer-term ($M=4.27$; $SD=1.52$) [$t(21)=2.48$, $p=0.022$], with longer-term scores showing a reduction in feeling lonely and lacking companionship. A reduction was also seen between the UCLA scores at baseline and the earlier time points, but was not significant (Table III). A significant difference was seen between the loneliness scores at baseline ($M=3.40$; $SD=1.38$) and up to 6 months ($M=2.77$; $SD=1.37$) [$t(34)=3.06$, $p=0.004$], showing a reduction in feeling lonely. A non-significant reduction was seen between the baseline loneliness scores and the other time points.

< Insert Table III about here >

Small sub-group sizes were a factor when considering members by sex and age, particularly at later time points. For both the UCLA and loneliness measures, female MC members had higher mean scores at baseline but lower scores (less lonely) at almost every other time point. There was no significant effect for sex at any time point (Table IV). Younger members had higher scores (worse loneliness) at almost each time point across both measures. There was a significant effect for age at baseline for both measures with younger members ($M=7.10$, $SD=1.60$) having higher scores than older members ($M=5.20$, $SD=2.12$) for the UCLA scale [$t(33)=2.55$, $p=0.016$], and also for the loneliness question [$t(34)=2.20$, $p=0.035$] ($M=4.00$, $SD=0.94$ compared to $M=2.81$, $SD=1.60$).

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3 < Insert Table IV about here >
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6 *Findings for family carers*

7 Of the 691 carers, 139 had a valid baseline score for at least one loneliness measure, with 45 also
8 having a valid score for at least one follow-up time point. The male/female split was similar for those
9 included in the analysis (73.1% female) compared to the wider MC population (72.1%). Carers in the
10 analysis were generally younger with 21.0% aged 75 or over when they joined the MC, compared to
11 40.4% for the wider MC population. They were also more likely to be a partner or spouse, but at a
12 higher rate than for the wider MC population (80.0% compared to 59.9%) (Table I). Mean loneliness
13 scores showed a general trend for increasing (worsening) over time (Table II).
14
15

16 A significant difference was seen between the UCLA score for carers at baseline ($M=4.75$; $SD=1.42$)
17 and in the longer-term ($M=5.92$; $SD=1.88$) [$t(11)=-3.02$, $p=0.012$], showing an increase in feeling
18 lonely and lacking companionship. A non-significant increase was seen between the baseline UCLA
19 scores and other time points (Table V). There was a significant difference between the loneliness
20 score at baseline ($M=2.17$; $SD=1.43$) and up to 12 months ($M=2.89$; $SD=1.02$) [$t(17)=-2.40$, $p=0.028$],
21 with the 12-month scores showing an increase in loneliness. The increases seen between the
22 baseline scores and the other time points were not significant.
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25 < Insert Table V about here >
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28 Low numbers were a factor for all three sub-groups, and no significant effects were seen for sex,
29 age, or relationship to the MC member (Table VI). Male carers had higher scores (worse loneliness)
30 at each time point across both measures, as did older carers and partner/spouse carers.
31
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33 < Insert Table VI about here >
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35 Discussion

36 This study identified that MCs impact members and carers differently regarding loneliness and social
37 isolation. While members saw an overall improvement with a significant reduction in feeling lonely
38 and lacking companionship in some cases, carers felt significantly more lonely and lacking
39 companionship, particularly when they had been at an MC for 12 months or more.
40
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42 These findings reflect how carers are known to engage with MCs, as members are active participants
43 but many carers leave to have a break or do other jobs. Consequently, carers do not join in with
44 activities and do not benefit from the social aspects of being part of a group in the same way as the
45 members. Carers may attend carer groups run by MCs, but as these focus on support and
46 information rather than 'fun' they still miss out on the social element. Combining educational
47 support and social activities may be a more effective approach (Cattan *et al.*, 2005). A previous study
48 identified that carers may not understand how MCs can help them and so not prioritise their own
49 attendance (Morton *et al.*, 2023). It recommended that MCs should be clear about the benefits to
50 family carers, consider ways for carers to socialise and experience peer support, and design activities
51 that will include and appeal to both members and carers.
52
53

54 Active participation is a key aspect when considering the effectiveness of interventions, particularly
55 when trying to reduce social isolation for older people, and a group format where people actively
56 participate can be more effective than a one-to-one format (Dickens *et al.*, 2011; Franck *et al.*, 2016).
57 It is therefore not surprising that when carers do not engage or participate fully in MCs and the
58 activities they offer, they do not experience the same benefits as the members.
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3 Although hampered by small sub-group sizes, the current study indicates that male and/or younger
4 MC members are potentially likely to feel lonelier than other members, while male and/or older
5 carers are likely to feel lonelier. Activities aimed mainly at women or older people may be off-putting
6 to men or younger members, suggesting the need to offer activities appealing to different
7 audiences. Catering to everyone's preferences is unlikely to be possible, but MCs are ideally placed
8 to tailor their offer and adapt to the needs of the group they support. 'The Essential Features of a
9 Meeting Centre' (redacted for review) are not a prescriptive, rigid definition of what an MC is and
10 how it should operate, instead providing a framework for developing an MC (redacted for review).
11 Consequently, although MCs should follow the same underlying ethos and principles, there is
12 flexibility and scope for each MC to be run in its own way. MCs are encouraged to engage with their
13 local community and take the lead from their members and carers about what they want to do at
14 the MC, which should result in activities appealing to the people they support. This aligns with
15 previous studies which found that more successful outcomes tend to arise when people are involved
16 in the planning and implementation, and interventions are based on existing community resources
17 (Findlay, 2003; Grenade & Boldy, 2008).
18
19

20 *Limitations*

21
22

23 This study reports on loneliness data captured as part of wider ongoing MC data collection activities.
24 A specific project focusing on loneliness may have increased the available data and enabled more
25 nuanced measures to be included.
26
27

28 Demographic information was relatively limited, but Swift *et al.* (2023) show it was broadly
29 representative of the wider MC population. However, nearly all members and carers were White
30 British, so it is unknown whether MCs would have a similar impact for people from other ethnic
31 backgrounds. As more MCs open in different communities across the UK, it is hoped that the
32 diversity of people supported by MCs will increase.
33
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35 The Covid-19 pandemic impacted data collection and is also likely to have affected loneliness as
36 members and carers were unable to attend MCs in person for a significant period (redacted for
37 review).
38

39 **Conclusion**

40

41 The data collected by MCs indicates that MCs can have an important role in helping to reduce
42 loneliness and social isolation for people with dementia. MCs also provide important support to
43 carers, but as many carers choose not to stay and actively participate in activities at the MC they do
44 not necessarily benefit from the social engagement aspect of MCs. Activities appealing to different
45 audiences, in particular members who are male and/or younger and carers who are male and/or
46 older, could broaden the appeal of MCs and encourage greater engagement from carers. The
47 underpinning 'adjusting to change' model combined with the Essential Features of an MC provide a
48 flexible framework for developing an MC to meet the needs of their local community.
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Table 1: Demographics of members and carers supported by MCs and those included in the analysis

		Members		Carers	
		MC population	Included in analysis	MC population	Included in analysis
Total number of people supported		1023	65	691	45
Number of MCs represented		29	10	28	6
Sex	Male	395	28	143	7
	Female	408	20	370	19
	Not recorded	220	17	178	19
Age on joining	<65	25	2	54	5
MC	65-69	36	5	23	3
	70-74	72	3	25	1
	75-79	101	3	26	3
	80-84	127	13	33	3
	85-89	109	6	7	0
	90-94	35	4	2	0
	95 and over	7	0	1	0
	Not recorded	511	29	520	30
Relationship to member	Partner/spouse	-	-	190	12
	Other	-	-	127	3
	Not recorded	-	-	374	30

(Source: Authors own work)

Table II: Mean loneliness scores for members and carers at each time point

	Time point	UCLA 3-item loneliness scale		Loneliness question	
		N	Mean score (out of 9)	N	Mean score (out of 3)
Members	Baseline	63	5.46	65	2.95
	Up to 6 months	35	5.40	35	2.77
	Up to 12 months	22	5.09	24	2.46
	Longer-term	22	4.27	22	2.23
Carers	Baseline	45	5.20	45	2.71
	Up to 6 months	30	5.33	30	2.97
	Up to 12 months	18	5.00	18	2.89
	Longer-term	12	5.92	12	3.00

(Source: Authors own work)

Table III: Paired t-test results for member loneliness scores comparing different time points

			N	Mean (SD)	t (df)	p
UCLA 3-item loneliness scale	Comparison 1	Baseline	35	5.80 (2.06)	1.34 (34)	0.190
		Up to 6 months	35	5.40 (1.96)		
	Comparison 2	Baseline	22	5.23 (1.88)	0.34 (21)	0.741
		Up to 12 months	22	5.09 (2.22)		
	Comparison 3	Baseline	22	5.68 (2.28)	2.48 (21)	0.022*
		Longer-term	22	4.27 (1.52)		
Loneliness question	Comparison 1	Baseline	35	3.40 (1.38)	3.06 (34)	0.004*
		Up to 6 months	35	2.77 (1.37)		
	Comparison 2	Baseline	24	2.54 (1.22)	0.30 (23)	0.765
		Up to 12 months	24	2.46 (1.35)		
	Comparison 3	Baseline	22	2.82 (1.56)	1.65 (21)	0.114
		Longer-term	22	2.23 (1.07)		

* indicates significant difference, $p < 0.05$

(Source: Authors own work)

Table IV: Member loneliness results at each time point by sex and age

		Time point	Male		Female			
			N	Mean (SD)	N	Mean (SD)	t (df)	p
Comparison by sex	UCLA 3-item loneliness scale	Baseline	28	5.07 (2.07)	19	5.74 (1.91)	-1.12 (45)	0.271
		Up to 6 months	15	5.20 (1.93)	12	5.17 (1.99)	0.04 (25)	0.965
		Up to 12 months	11	5.55 (2.21)	8	5.25 (2.38)	0.28 (17)	0.784
		Longer-term	10	4.30 (1.49)	5	4.00 (1.00)	0.40 (13)	0.694
	Loneliness question	Baseline	28	2.75 (1.38)	20	3.35 (1.57)	-1.41 (46)	0.167
		Up to 6 months	15	2.60 (1.18)	12	3.00 (1.28)	-0.84 (25)	0.408
		Up to 12 months	11	2.91 (1.22)	9	2.11 (1.45)	1.34 (18)	0.198
		Longer-term	10	2.30 (1.06)	5	2.20 (1.10)	0.17 (13)	0.867
			Under 75		75 and over			
Comparison by age	UCLA 3-item loneliness scale	Baseline	10	7.10 (1.60)	25	5.20 (2.12)	2.55 (33)	0.016*
		Up to 6 months	8	5.63 (1.85)	13	5.23 (2.28)	0.41 (19)	0.685
		Up to 12 months	2	6.50 (0.71)	13	5.00 (2.27)	0.90 (13)	0.384
		Longer-term	3	5.00 (2.00)	7	4.00 (1.15)	1.03 (8)	0.335
	Loneliness question	Baseline	10	4.00 (0.94)	26	2.81 (1.60)	2.20 (34)	0.035*
		Up to 6 months	8	3.00 (1.07)	13	3.00 (1.41)	0.00 (19)	1.00
		Up to 12 months	2	2.50 (0.71)	14	2.36 (1.55)	0.13 (14)	0.902
		Longer-term	3	3.00 (1.73)	7	2.43 (0.98)	0.68 (8)	0.513

* indicates significant difference, p<0.05

(Source: Authors own work)

Table V: Paired t-test results for carer loneliness scores comparing different time points

			N	Mean (SD)	t (df)	p
UCLA 3-item loneliness scale	Comparison 1	Baseline	30	5.30 (2.04)		
		Up to 6 months	30	5.33 (1.97)	-0.11 (29)	0.917
	Comparison 2	Baseline	18	4.72 (2.35)		
		Up to 12 months	18	5.00 (1.88)	-0.53 (17)	0.602
	Comparison 3	Baseline	12	4.75 (1.42)		
		Longer-term	12	5.92 (1.88)	-3.02 (11)	0.012*
Loneliness question	Comparison 1	Baseline	30	2.87 (1.38)		
		Up to 6 months	30	2.97 (1.30)	-0.46 (29)	0.647
	Comparison 2	Baseline	18	2.17 (1.43)		
		Up to 12 months	18	2.89 (1.02)	-2.40 (17)	0.028*
	Comparison 3	Baseline	12	2.33 (1.23)		
		Longer-term	12	3.00 (1.28)	-1.61 (11)	0.136

* indicates significant difference, $p < 0.05$

(Source: Authors own work)

Table VI: Carer loneliness results at each time point by sex, age and relationship to the MC member

		Time point	Male		Female			
			N	Mean (SD)	N	Mean (SD)	t (df)	p
Comparison by sex	UCLA 3-item loneliness scale	Baseline	7	5.29 (2.36)	19	4.68 (1.83)	0.69 (24)	0.497
		Up to 6 months	6	6.33 (1.86)	15	5.20 (2.14)	1.13 (19)	0.272
		Up to 12 months	4	6.00 (1.41)	8	4.63 (1.77)	1.35 (10)	0.208
		Longer-term	0	-	6	5.83 (1.60)	-	-
	Loneliness question	Baseline	7	3.14 (1.86)	19	2.53 (1.43)	0.90 (24)	0.377
		Up to 6 months	6	3.17 (1.60)	15	2.80 (1.01)	0.63 (19)	0.534
		Up to 12 months	4	3.50 (1.00)	8	2.50 (0.93)	1.72 (10)	0.116
		Longer-term	0	-	6	2.67 (1.21)	-	-
		Under 75		75 and over				
Comparison by age	UCLA 3-item loneliness scale	Baseline	9	5.22 (1.99)	6	5.83 (2.40)	-0.54 (13)	0.600
		Up to 6 months	8	6.25 (2.05)	4	6.75 (2.06)	-0.40 (10)	0.700
		Up to 12 months	3	5.67 (2.52)	2	6.50 (2.12)	-0.38 (3)	0.728
		Longer-term	1	6.00 (-)	2	7.00 (1.41)	-0.58 (1)	0.667
	Loneliness question	Baseline	9	3.11 (1.54)	6	3.17 (2.04)	-0.06 (13)	0.953
		Up to 6 months	8	3.25 (1.04)	4	4.00 (1.15)	-1.14 (10)	0.280
		Up to 12 months	3	3.33 (0.58)	2	3.50 (2.12)	-0.14 (3)	0.898
		Longer-term	1	3.00 (-)	2	4.00 (0.00)	-	-
		Spouse/partner		Other relation				
Comparison by relationship	UCLA 3-item loneliness scale	Baseline	12	5.67 (2.15)	3	4.33 (2.31)	0.95 (13)	0.359
		Up to 6 months	8	7.13 (1.89)	3	4.67 (1.53)	2.00 (9)	0.076
		Up to 12 months	4	6.50 (1.73)	2	4.50 (2.12)	1.26 (4)	0.277
		Longer-term	3	6.67 (1.15)	0	-	-	-
	Loneliness question	Baseline	12	3.17 (1.85)	3	2.33 (1.53)	0.72 (13)	0.487
		Up to 6 months	8	3.75 (1.16)	3	3.00 (1.00)	0.98 (9)	0.353
		Up to 12 months	4	3.50 (1.29)	2	3.00 (0.00)	0.52 (4)	0.633
		Longer-term	3	3.67 (0.58)	0	-	-	-

(Source: Authors own work)