ASI Virtual and Telephone Service Evaluation

Evaluating new services during COVID-19

December 2020

THE ALZHEIMER SOCIETY of IRELAND

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The COVID-19 pandemic poses a significant risk for people living with dementia and their carers. There are an estimated 64,000 people with dementia in Ireland today, with 63% living in our communities and approximately 60,000 carers of someone with dementia. The care delivered by them accounts for 48% of the overall cost of dementia in Ireland[1]. There are an estimated 6,000 to 10,000 people living with dementia who live alone in the community[2]. Living with dementia at any time brings everyday challenges for the person and those around them. The challenges from the impact of COVID-19 are making daily life considerably more difficult and exacerbating the vulnerability of this group.

The outbreak of COVID-19 forced The Alzheimer Society of Ireland (ASI), the largest dementia specific service provider in Ireland, to temporarily suspend all its 48 day care centres and vital supports (e.g. Social Clubs, Alzheimer Cafes, Support Groups). On April 1st 2020, in the immediate aftermath of the cessation of dementia services, The ASI carried out research with 150 carers and people with dementia to understand the challenges and concerns they faced. Also included were the views of Community Champions from the Dementia: Understand Together initiative and data from The ASI's Helpline and Dementia Advisers (DAs). In this initial survey, challenges included the following:

- Pervasive loneliness and social isolation among carers,
- Lack of routine, leading to deterioration of symptoms of dementia and responsive behaviours, such as agitation, wandering and apathy,
- Fear and anxiety among carers and people with dementia,
- Carer stress and fear of being unable to cope, feeling isolated, helpless and overwhelmed by caring workload.

The findings of this initial COVID-19 survey[3] report detailing the challenges experienced by people with dementia and family carers and exploring what supports they needed, were instrumental in informing The ASI's response to the temporary cessation of services and in re-designing a new suite of services to address need during COVID-19.

1 Pierce, M., Cahill, S., and O'Shea, E. (2014). *Prevalence and Projections of Dementia in Ireland*, 2011–2046, Genio, Mullingar.
2 As above.
3 The Alzheimer Society of Ireland. 2020. *COVID-19: Impact & Need for People living with dementia and Family Carers* https://alzheimer.ie/wp-content/uploads/2020/04/Research-report-Covid19-Final.pdf

This new suite of remote services was developed to complement the existing services that are still operating during COVID-19, such as the Dementia Advisor (DA) service, the National Helpline and Online Family Carer Training. The new services were developed with the input of people living with dementia, family carers, ASI staff, and other stakeholders. Each of the new services, outlined below, has been evaluated to understand to what extent they meet the needs of people with dementia and family carers:

1 **Alternative Service Therapy**:

This service, aimed at people living with dementia and their family carers who availed of day care prior to COVID-19, provides social calls and activity packs. This service commenced mid-May and was evaluated at baseline, week 6 and week 12.

2 **Dementia Nurse 1:1 Service**:

A free call-back service which offers people with dementia and family carers the opportunity to book a 1:1 phone session with a Dementia Nurse to discuss specific issues that may be arising for them.

3 **Virtual Alzheimer Cafe**:

This service is intended to mirror previous face-to-face Alzheimer Cafes. They are hosted weekly via Zoom. Each cafe includes a talk from a speaker (e.g. lawyer, dementia adviser) and a question and answer session.

4 **Online Support Group**:

This service is a dedicated space for family carers to find information and resources of interest to them. It is intended to enable face-to-face support groups in the absence of usual face-to-face carer support groups.

Section 1

Alternative Supports Therapy (AST): Social Calls & Activity Packs

1 Alternative Supports Therapy (AST): Social Calls and Activity Packs

1.1 Aims and Implementation

Therapeutic Activities and Social Engagement Call Support was developed for people living with dementia and their family carers who attended day-care prior to COVID-19. It was developed in response to the cessation of dementia services and to meet need in the absence of usual day care supports. This service seeks to address needs and mitigate issues arising from the temporary closure of day care, recognising that a lack of activity opportunities can result in responsive behaviours, boredom, loneliness, and the need for mental and social stimulation while reducing carer stress. The aim of the service is to engage with the client and family carer either through a social engagement call and /or a variety of activities disseminated, which are stimulating and varied to maintain well-being.

This service takes the form of social phone calls and activity packs that are posted directly to clients. ASI clients stated their preference for either social calls, activity packs or in some cases both. The activity packs contain a variety of recreational materials including crosswords, quizzes, colouring exercises and musical CDs that family carers can use with the person with dementia.

AST commenced in mid-May, and prior to this the local ASI Activities Support Leads engaged with ASI clients and their carers to understand their preference for social phone calls and activity packs. Social calls take place most often on a weekly basis while activity packs were sent mainly by post to clients on a monthly basis. In total 2,313 Activity Packs have been distributed to date, 16,407 calls (24th March to 1st May – 5,681 / 5th May to 23rd August– 10,726) and 2,593 hours have been spent making phone calls.

To date

2,313
Activity Packs distributed

16,407
Calls made

2,593
Hours spents making phone calls

1.2 Objectives of Evaluation

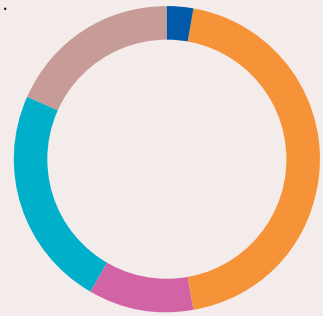
ASTs were evaluated from the outset in order to elicit insight into sustainability, development and possible future funding for the project. Baseline data was gathered through surveys at week 1 (w/b 18th May), and further surveys were carried out at week 6 (w/b 29th June) and at week 12 (w/b 10th August). The evaluation sought to address the following question:

To what extent have ASTs been effective in meeting needs and maintaining the well-being of people with dementia and carers during COVID-19?

1.3 Participants and Demographics

- Baseline data was gathered from 142 client respondents including carers and people with dementia.
- 95% of respondents consisted of carers, and 5% were people living with dementia
- 42% of respondents identified as spouses/partners, while 55% were either sons or daughters of the person with dementia.
- 45% of respondents were aged between 40–59 years, 23% aged between 66–75, and 17% aged 75 plus, and 12% aged 60–65.
- The majority of respondents (55%) have used ASI's day care service, and 14% have availed of DAs, 16% of family carer training, and 13% of home care.
- 46% of respondents are availing of both social calls and activity packs, 41% of respondents are availing of ASI's social calls only, and 13% are availing of activity packs only.

Figure 1.1
Age range of participants



3% Ages 26 – 39

44% Ages 40 – 59

11% Ages 60 – 65

23% Ages 66 – 75

18% Ages 75+

Figure 1.2
Carer Relationship to Person with dementia

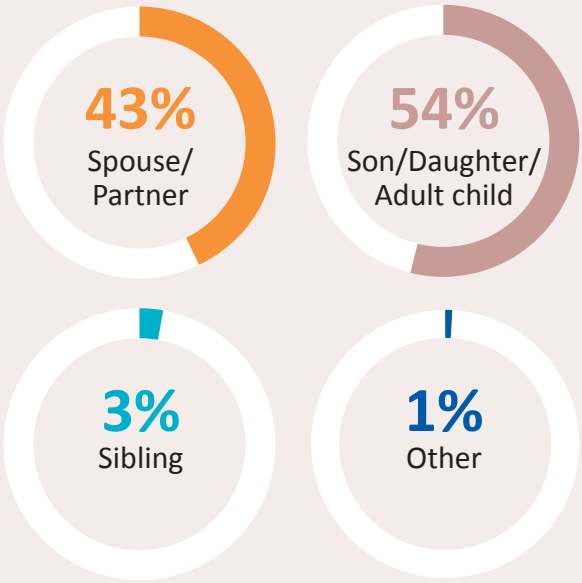


Figure 1.3
ASI Services used previously

- Day Care **56.02%**
- Alzheimer Cafe **4.63%**
- Support Group **5.56%**
- Family Carer Training **7.41%**
- Social Club **2.78%**
- Home Care **13.43%**
- Dementia Adviser **6.94%**
- Other **3.24%**

1.4 Experiences and Coping

During initial baseline surveys carried out during week 1 of the new service, respondents described caring under immense stress and in difficult circumstances,

> "My children are autistic and that's an extra challenge. My mother is also blind, so that's very difficult."

> "My daughter has a disability and the combination of both and my husband with dementia is overwhelming, and incredibly stressful. My husband is very agitated at the weekend and this is very difficult."

Exhaustion and loneliness were commonly experienced,

> "It's very difficult as husband is very moody and changeable in nature, I have my own health difficulties, and have no-one else to help me. My husband still has a lot of energy and never stops talking. I'm exhausted. The toileting is very difficult and I have to help him, and he has accidents. He's very stubborn also and doesn't follow instruction."

> "Caring is taking such a toll, and I have no social life. It's so lonely and I have no one to talk to. Personal hygiene is so challenging especially for a son when caring for his mother."

Fear and desperation were frequently echoed, as one carer simply stated, *"I don't know how much longer I can take it."*

Even at this relatively early stage when services had ceased operating only weeks, carers were already observing alarming decline in the person with dementia,

> "My father's condition has deteriorated since he stopped day care. He misses it so much. He is strong and able bodied and he misses the routine. Keeping him occupied is so difficult, he walks all day and never stops. It's stressful."

> "Since the lockdown and daycare facilities have been postponed, I've noticed a decline in my father's cognitive abilities. He becomes frustrated with reading and pretends to lose his glasses to avoid that task! Simple tasks like folding clothes are now a huge challenge for him. Even his speech has declined, forgetting key nouns and so engaging in conversations is a great challenge now. I am a teacher, working from home and have two young daughters (age 9yr and 7yr) so I can't sit with him all the time. It's all too tricky!"

Some respondents were already receiving weekly calls from ASI staff, and described staff as immensely supportive, a "*godsend*" and expressed gratitude for the continued support,

> The calls are a lifeline and I don't know what I would without them. I look forward to the calls each week. The support from staff is unreal, and they take their time and don't rush and really listen. It means the world to me."

> "The staff are amazing, they're incredible, so supportive, friendly and I'd be lost without them. They're so understanding and the phone calls are great, I love them. They're like family."

> "[The ASI staff member] is a very kind person and is interested in my mother and her health and well-being. This is the only person who calls us to find out how we are coping and if we need anything. I appreciate her concern."

> "Thank you to you all for your hard work, the weekly phone calls are so lovely. It's so nice to speak with a nurse, and someone who knows Dad and are able to guide me, support me and even just to hear words of affirmation 'you're doing a good job'. The days are long, challenging for everyone so may I say a huge thank you to you all for your kindness, helpful resources, patience and dedication."

It is of concern that some respondents said that without the continued support of ASI, they would not be able to continue, with one carer stating she would be *''hanging from a tree'',* or another*, "I would have ended everything."*

During initial surveys, respondents expressed concern about re-opening of ASI services, in particular day care, as the person with dementia misses the activities and social connections,

> ASI services, day care, has changed my life and brought great benefits to my husband. It was like a light switched on when he started going. His face lights up. I would really like day care to re-open. I don't know where we'd be without the Alzheimer Society."

A person with dementia explained,

> I have great times in the day care, games and all sorts of things, and I miss it all terribly. Its great company, a laugh, and craic. We have events, dances, songs and I miss it so, so much. I feel sad about it, the weeks and days are so long without it."

Another person with dementia echoed this sentiment*, "The day is long and I really miss the day care services. I try to have hope, I have to keep going, that's all I can do."*

Employment responsibilities were also highlighted as a concern,

> In these unreal times – we have adjusted to our new day - but I worry when I have to return to work – how my partner will adjust to me not been there."

> I'm feeling extremely stressed out, also having to work full time from home."

1.5 Role of Alternative Support Therapy

Respondents were asked why they decided to receive the new service, and in response highlighted why they felt it was important,

Staying in touch, engaged and maintaining contact

> It's nice to keep in contact and to know my Mother will not [be] forgotten."

> "It's nice to have a connection with another person, I would try anything, I'm so desperate. If anything helps my husband, I'll try it."

Fear and desperation

A person with dementia explained,

> I'm terrified of the virus, afraid to leave my home and so scared. I don't know when I'll see my friends at the day care centre again. [The ASI staff member] from the centre is great, calls me, asks me if there's anything she can do. I feel connected in some ways."

Not being alone

> I know it's good to talk. I don't want to be on my own."

> "A direct line of support and a conversation with people who understand the issues. You feel you are not alone."

Understanding and reassurance,

> It is nice to speak to someone who understands the difficulties of everyday caring for two people with dementia, one who is my husband and the other is my brother."

> "If I was feeling overwhelmed, the person that contacts us really calms me down, very reassuring. Anything at all you can ask him. The back-up and support is reassuring."

Stimulation and staying active

Keeping busy and also ensuring the person with dementia continues to be stimulated were key considerations,

> It's to keep busy, and break up routine, and give us fun things to do together. But I'm at the end of my tether some days and feel like I'll crack up."

> "Mum is bored and definitely declining without the care. Dad and I are keeping her stimulated but it will be nice to have different things to do. Anything new is great."

> "To relieve boredom, for motivation, for a break, I need something different, I need more support and something different. My husband is very challenging, very difficult behavior."

A source of support and Information,

> It's a great backup, helps me keep me up to date with opinions, information, knowledge…I can ask questions if anything comes up."

Trust

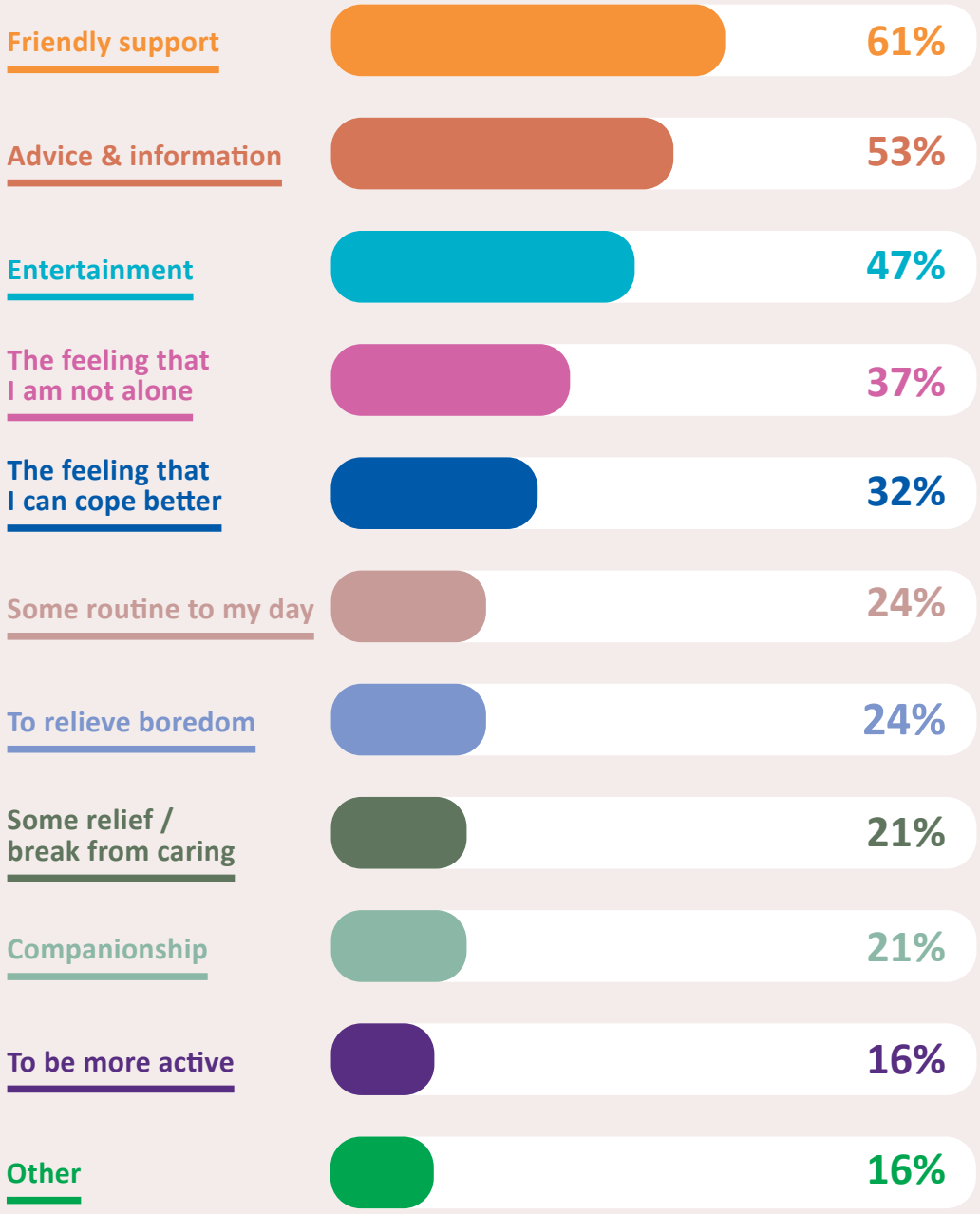
Some respondents chose to receive the new services because they trust the advice of ASI and the support offered by staff,

> It was on the recommendation of the day care centre. We trust their advice."

1.6 Client Expectations

When asked what they hoped activity packs and social calls might provide, respondents most commonly selected *Friendly Support, Advice & Information,* and *Entertainment.*

Figure 1.4
Expectations of the service

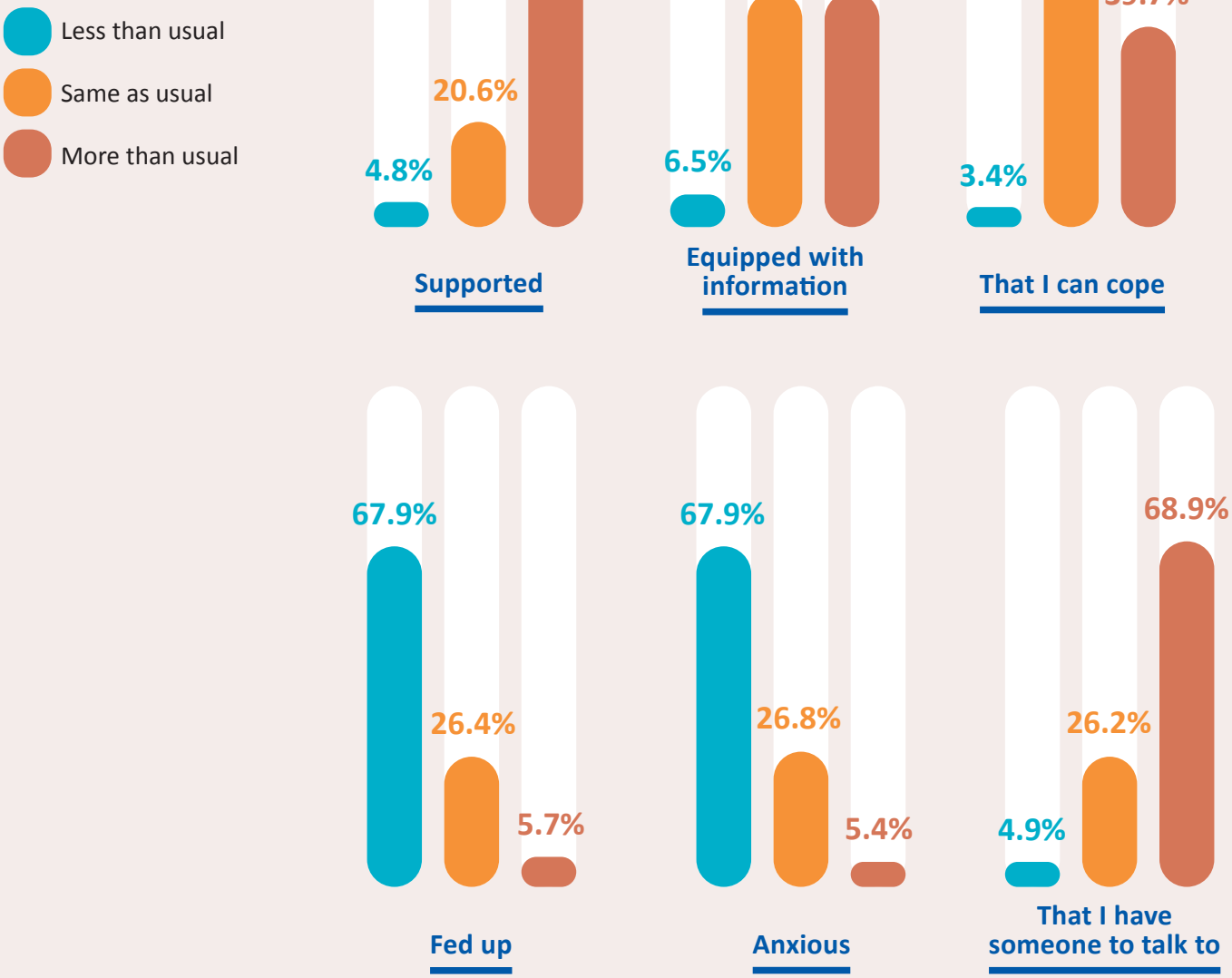


1.7 Week 6: Experiences and Perceptions

At week 6, respondents were contacted again and asked how they were experiencing the activity packs and social calls and how the services made them feel.

Social Calls (Week 6)

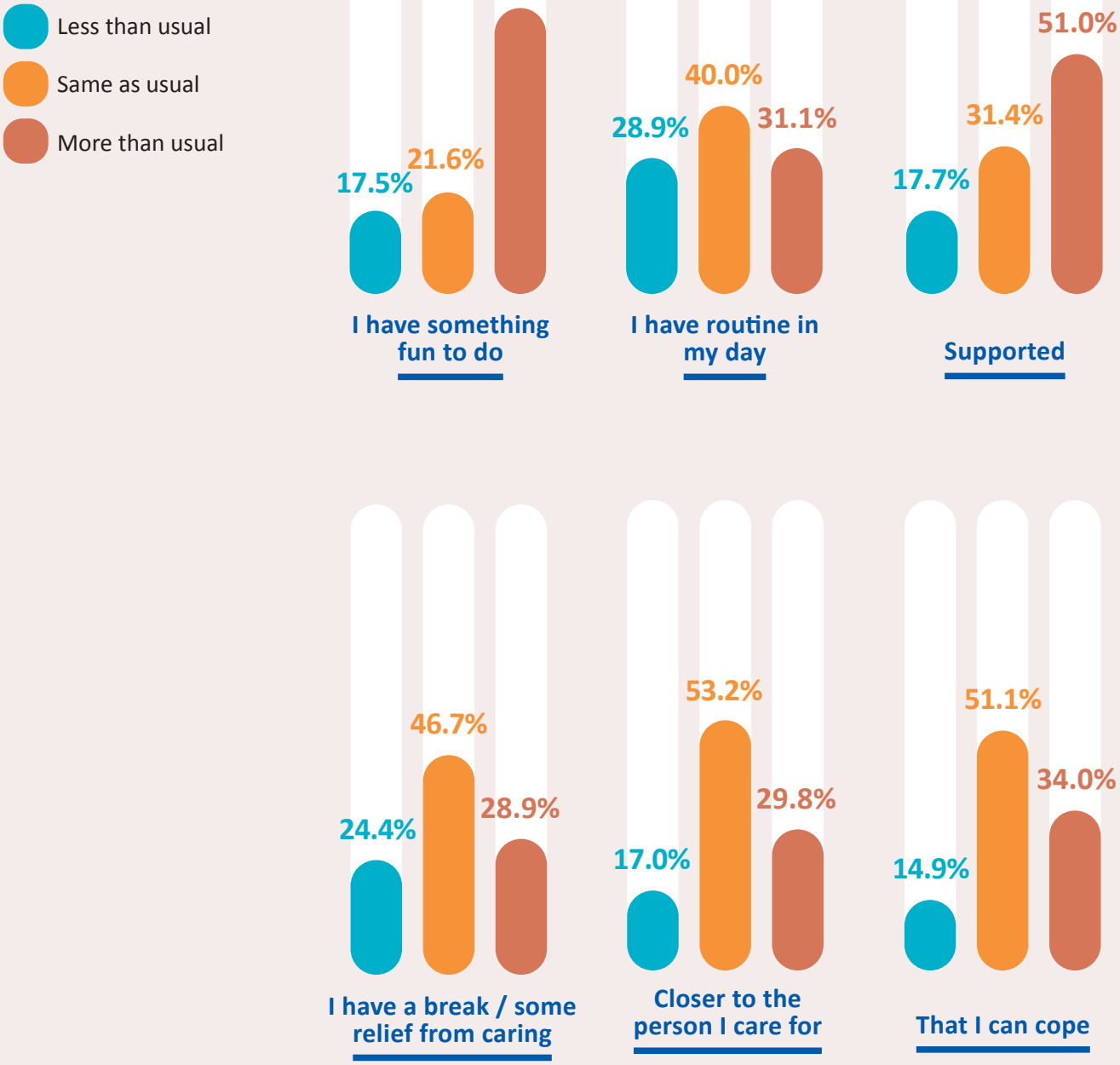
Figures 1.5 – 1.10
Experiences and Perceptions of the Social Calls at Week 6



Activity Packs (Week 6)

Figures 1.11–1.16

Experiences and Perceptions of the Activity Packs at Week 6



Figures 1.17 – 1.18

Experiences and Perceptions of the Activity Packs at Week 6

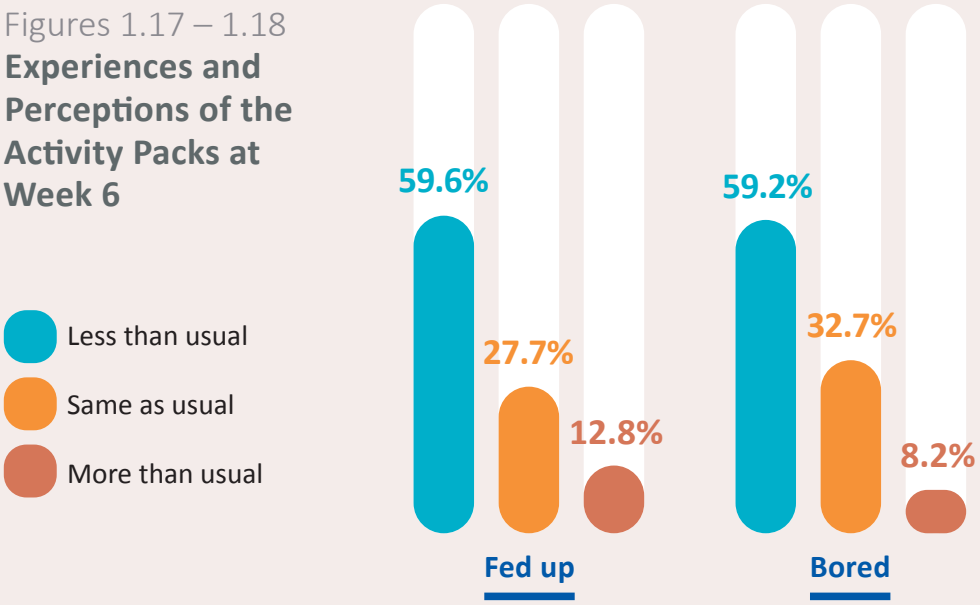
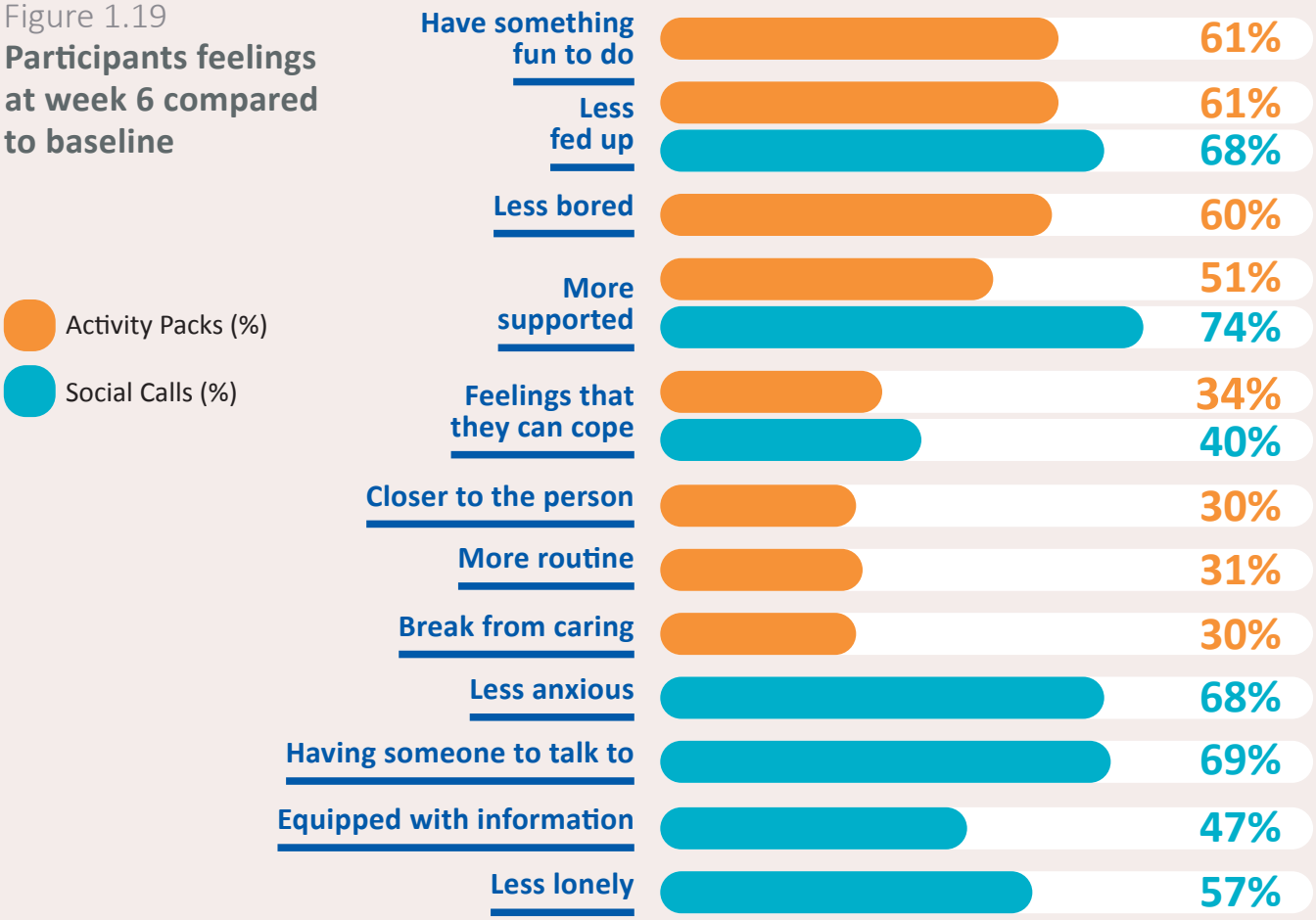


Figure 1.19

Participants feelings at week 6 compared to baseline



Respondents were asked what they liked or found helpful about the activity packs, and overall provided very positive responses,

> Good variety of material, ideas to plan and do daily, loves the cross-words, loves the colouring, family fun, words of songs, poems, puzzles."

> "The variety of tasks are amazing", "Keeps mum occupied, good way of interacting."

> "I feel supported - not everyone understands what caring for someone with dementia feels like."

Regarding social calls, not being forgotten was mentioned numerous times,

> Knowing my mother isn't forgotten about / To know that someone is thinking of mam."

Alleviating loneliness was as indicated as an important benefit of social calls,

> I think the services offered by your society are excellent and I really appreciate what you all do. The fact that someone comes and just chats to mum a few times a week is great and just what mum needs. Loneliness is mum's worst problem and she loves when people call."

For some the social calls were a "*lifesaver*", and the advice offered by staff during social calls was of significant benefit for carers, especially those dealing with increasing responsive behaviours,

> I longed for the weekly calls to speak with someone and bounce medical questions off."

> "Thank you - the calls gave me the time to cry, ask questions, receive guidance and help to continue in the new 24/7 Care role."

1.8 Week 12: Experiences and Perceptions

At week 12 when respondents were again surveyed to ascertain if they continue to benefit from the activity packs and social calls, similar positive responses were echoed,

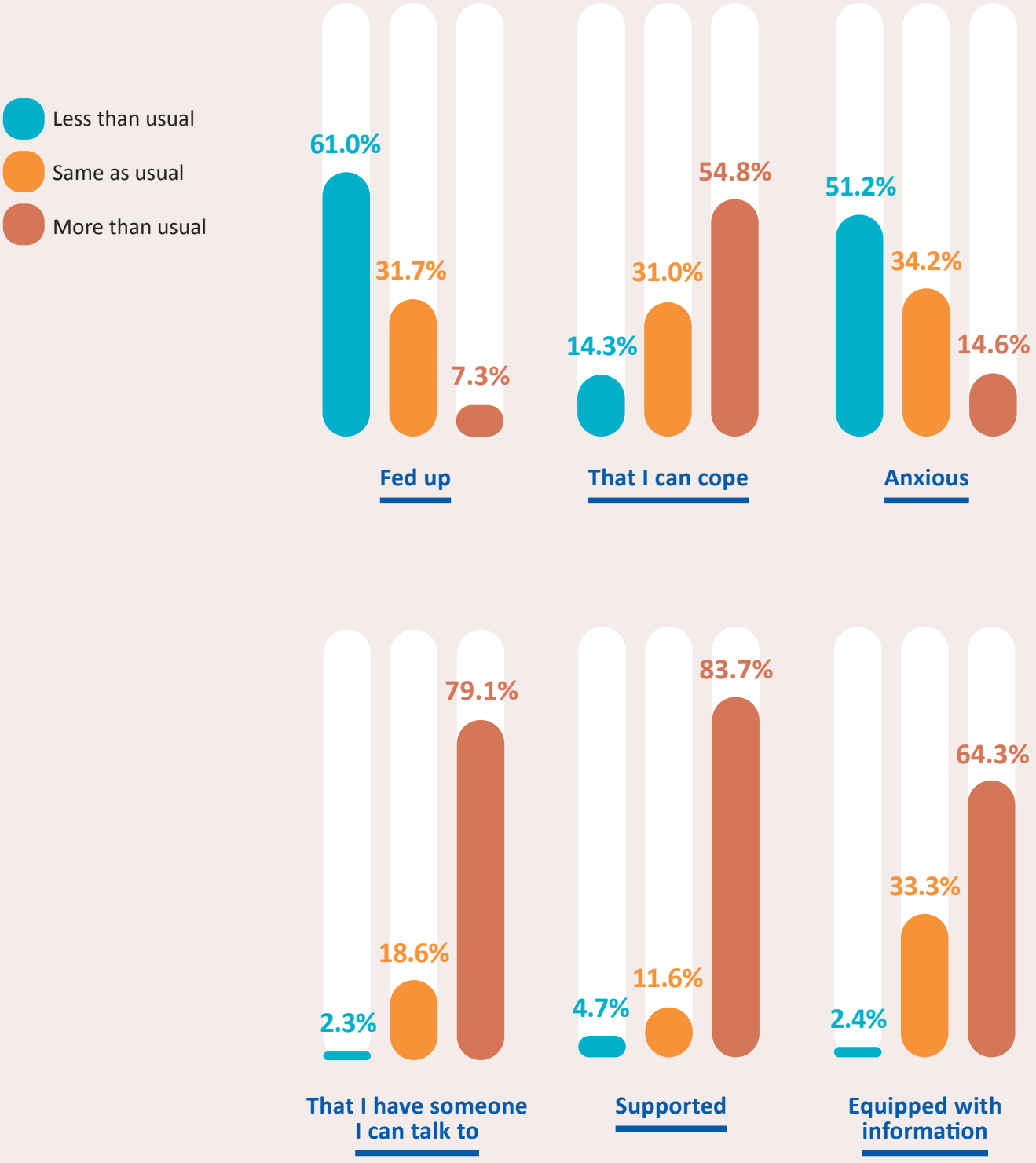
> He likes the word search! Loves the achievement! Loves the music, brought a bit of fun, the quizzes are good, something different that we wouldn't have had otherwise"

> "Oh my god they're brilliant! Social calls are keeping the contact going making me feel appreciated as a carer."

At week 12 respondents' experiences of the new service were notably very similar to week 6 in all categories below,

Social Calls

Figures 1.20 – 1.25
Social Calls



Activity Packs

Figures 1.26 – 1.32
Activity Packs

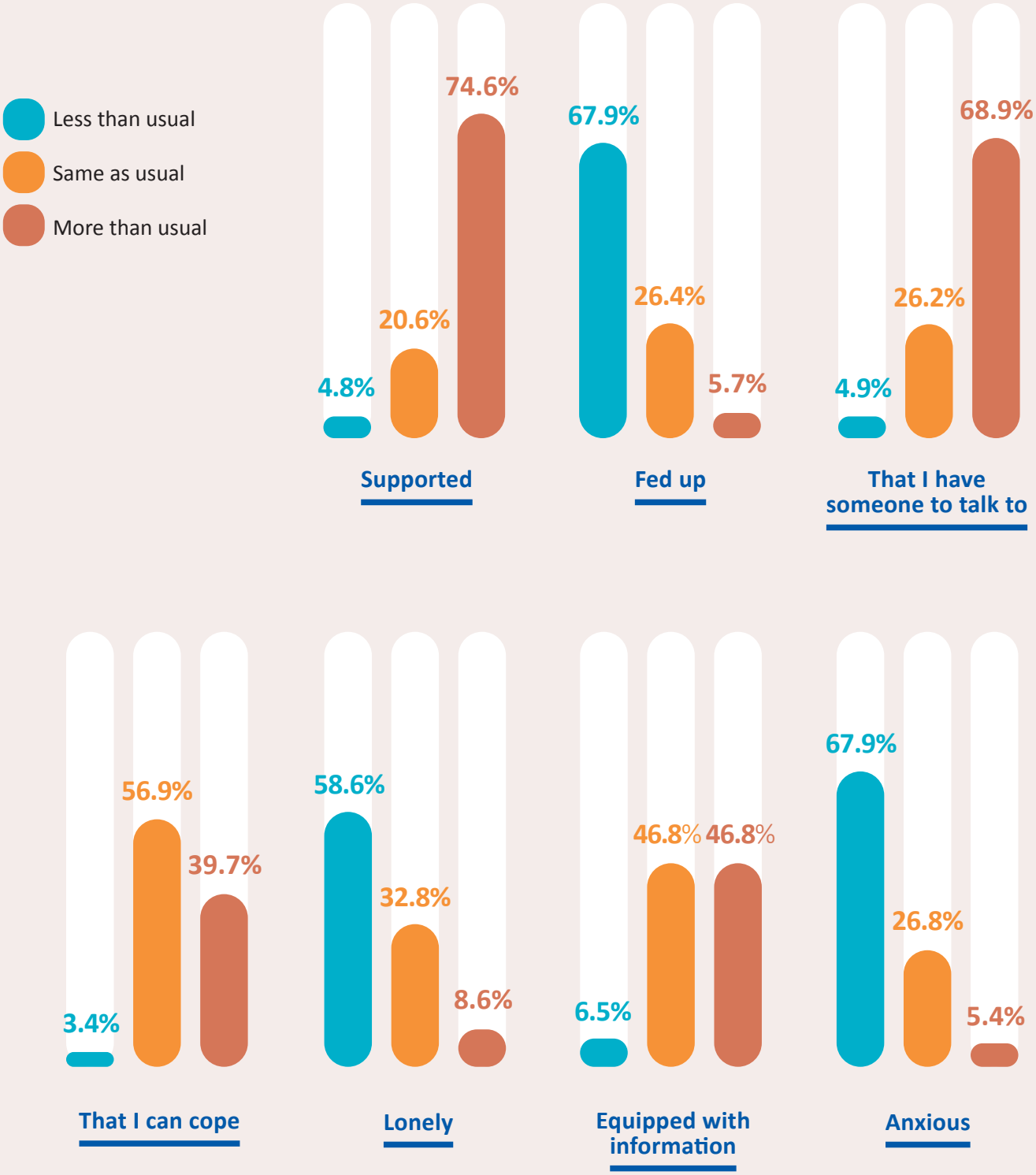
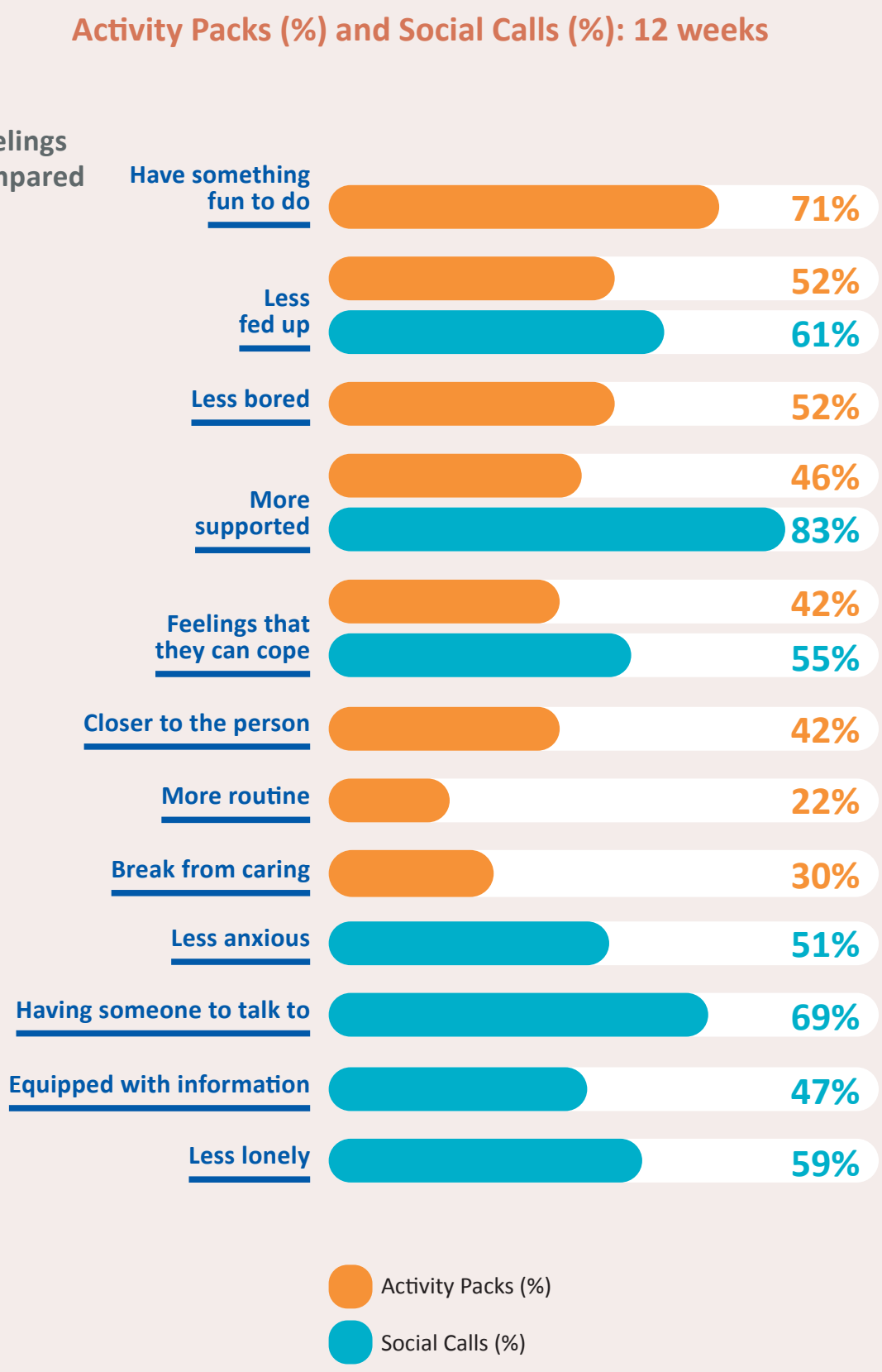


Figure 1.33

Participants feelings at week 12 compared to baseline



1.9 Suggestions for Improving Alternative Support Therapy

Respondents were asked if there was anything they disliked or would like to be changed about the activity packs and social calls. The general consensus from respondents is that they are satisfied with the activity packs, and many respondents simply responded *"no"* to this question.

Two respondents alluded to stigma and fear, and expressed concern that mentioning Alzheimer's on the material was upsetting to their loved ones,

> "Sending him things marked with Alzheimer's on them are not a good thing, as we've basically just been telling him he was going to a social club. It was addressed to his name and he wouldn't stop talking to my brother for 2 days after receiving them as he was so worried about it."

Other carers suggested that additional information in the activity packs directed at carers would be useful,

> "A separate section for carers with information on how Alzheimer's will progress and general information on the disease. Ideas to keep loved one mobile e.g. walk in garden picking flowers."

More gender specific information was also suggested, and more material directed at men. A small number of respondents felt that the activity packs were too difficult,

> "They were a bit too hard. Mum is a country lady with limited education. Her interests were all Mass, cattle etc. It was geared towards city slickers."

Some respondents suggested that the activity packs are best suited to those with early onset dementia,

> "My husband is at the stage with his dementia where he unfortunately can't do anything more than the colouring. They are a great idea, but are a bit too advanced for him. He just can't really comprehend what he's supposed to be doing. I actually find them quite interesting when I'm doing them myself. Maybe they are better for people with early stages of dementia."

Some respondents offered practical suggestions,

> "Some of it can be tricky. To make the activity pack more colourful itself would be great, rather than all white. It would be more appealing. The colours would make him curious."

Also noted is that four respondents stated that they would prefer less frequent social calls.

86%
of respondents would like to see **activity packs** continuing in the future.

90%
of respondents would like to see **social calls** continuing in the future.

Respondents were asked if they would like to see the Activity Packs continuing in the future, and 86% responded positively while 90% stated that they would like to see the Social Calls continuing in the future. Respondents were asked if they would like to see the Activity Packs continuing until regular services re-open, and 50% agreed. Another 50% agreed that they would like the activity packs to continue even after services re-open.

1.10 A Growing Crisis

The absence of services has adversely affected the health and wellbeing of some people with dementia and led to a decline in dementia symptoms, also identified in the recent research report, *Caring and Coping with Dementia During COVID-19*. In such cases, the activity packs and social calls are insufficient and simply cannot meet particular needs, and this was apparent in week 6,

> "Didn't really hold mum's attention. She's nearly too far gone for this. Her attention is not what it used to be."

Respondents recognised that additional support is essential and critically needed,

> "[The ASI staff member] has been very nice but there's not much support that can really be provided now and my Mum is really suffering because of this."

> "It's very difficult to care for my father. The calls and packs are nice for me to do, but do nothing for him. I really am just anxiously awaiting the re-opening of the centre."

> "I'm basically asking the same question every single week, when are the centres going to be back open?"

It is deeply concerning that at week 6 of the evaluation, many callers were experiencing signs of burn-out and were clearly in crisis. The ASI Research team who made the survey calls to clients referred numerous clients to The ASI national Helpline and onto the Dementia Nurse service. In some instances, the team had immediate concerns about the welfare and wellbeing of some carers, and contacted the Helpline with carer details.

Some carers became emotional and wept during the phone calls and the surveys as they described their deeply distressing circumstances. Others were relieved to have the opportunity to talk about their difficulties and surveys designed to last 5 minutes sometimes took 30 minutes to complete. Some surveys were not completed because it was not deemed appropriate to

continue with the survey given the level of distress. A number of respondents explained that the survey was no longer relevant as the person with dementia had entered long-term care as they, the carer, were no longer able to cope.

At week 12 (week of 10th August) it became clear that some of the distress has turned to deep-seated frustration and anger as the crisis continued with no end in sight for many. While some carers reported that the ease of restrictions was helpful, others were adamant that nothing had improved for them, *"very tough, very challenging… no change, no difference".*

Fear and anxiety continued to be pervasive among carers,

> "Just worried if I got sick how mother would be cared for, she would need to be in a care home. How would this happen in an emergency. Please God it won't happen."

Social distancing and hygiene guidelines still presented challenges,

> "It's hard to get mother to understand wearing a mask and social distancing and to keep washing hands. She can't see the need for it. She doesn't think she'll get the virus."

The sense of not being able to cope any longer and feeling utterly overwhelmed was now more acute,

> "Very difficult, struggling, I've ended up in hospital for stress. Mum has dementia. My feeling is that something is going to give."

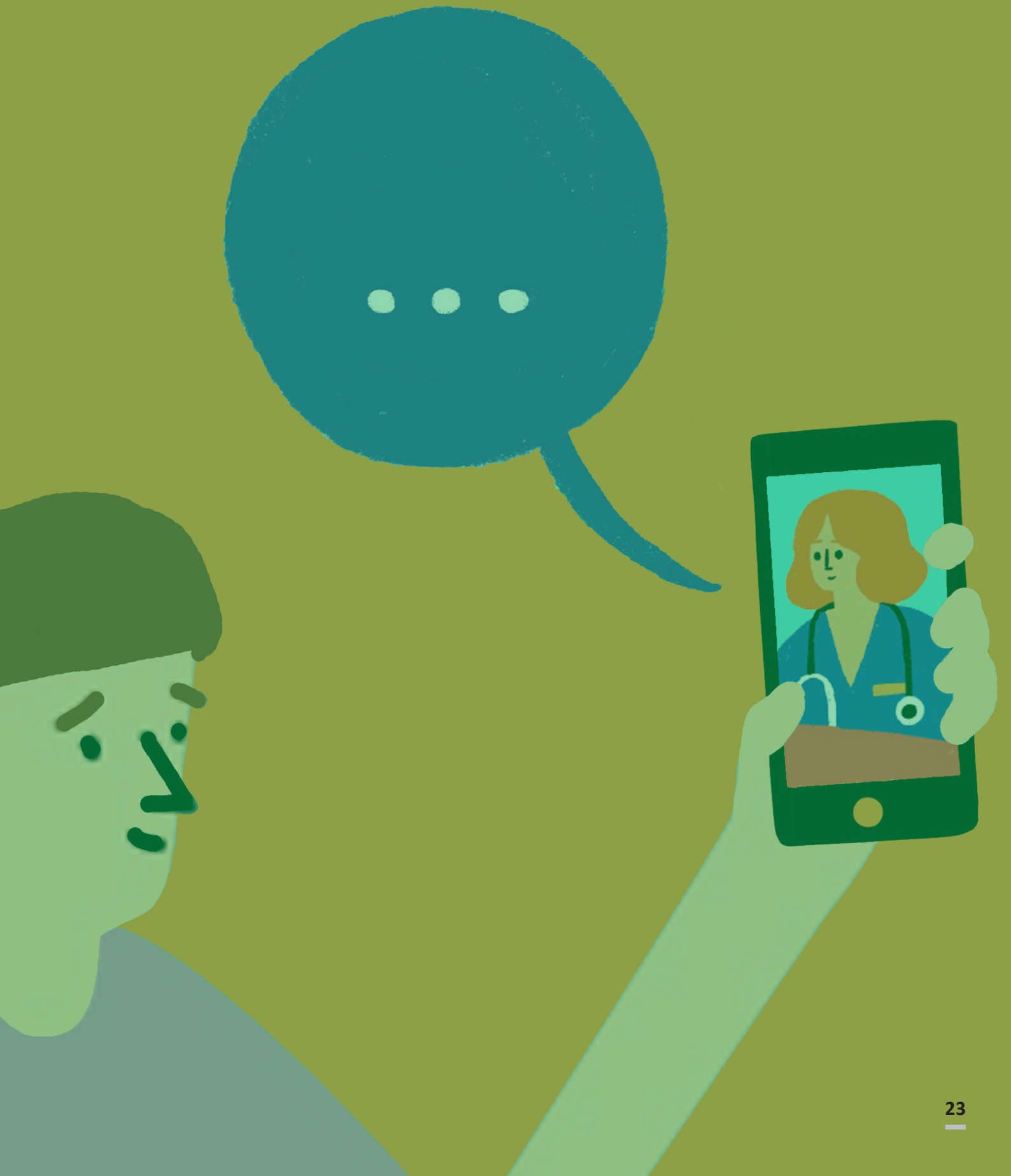
> "Just barely coping and taking one day at a time. It's very hard with nothing to look forward to and to try to motivate two people who rely on me for everything. Carers have been forgotten big time."

1.11 Summary of Key Points

- The role of ASI staff in providing support to carers and people with dementia in the absence of usual service is paramount, and experienced by clients as critical and essential. Prior rapport and trust with clients has been vital in maintaining this supportive relationship.
- AST has a very important role to play during COVID-19 in terms of maintaining links and connections with carers and people with dementia, providing consistent support and reassurance.
- AST services have played a vital part in ensuring that ASI clients continue to feel supported, feel there is someone they can talk to, managing boredom, loneliness and anxiety. Emotional support is a key benefit of AST services. Reassurance and the feeling that one can cope are also important benefits.
- The practical support of AST in terms of information and advice is also identified. This is especially crucial as many people with dementia experience a decline in symptoms during COVID-19.
- As time passes and vital services remain closed, the needs of people with dementia and carers continue to grow. AST alone cannot meet the extent of these needs. It is clear that for some respondents the needs of the person with dementia were simply too great in order to be appropriately met by the activity packs and social calls.
- It is likely that AST services would be ideally located within a broad spectrum of services that include a variety of person-centred dementia care. Indeed, many respondents would like to continue receiving AST even when normal services resume.
- As many counties in Ireland have inadequate services and many people experience difficulties accessing dementia supports, it is possible that a service delivered by phone and /or post, such as AST, could play an important role in reaching difficult-to-access cohorts.
- The crisis for carers and those living with dementia continues to deepen as services remain closed, and many carers are at breaking point. This presents serious concerns for the health and well-being of carers and the health and safety of people living with dementia.

Section 2

Dementia Nurse Service



2 Dementia Nurse Service

2.1 Background and Context

The temporary cessation of dementia services in March 2020 and the guidelines around social distancing and cocooning presented new and significant challenges to people with dementia and their families. In many cases it led to deterioration in dementia symptoms (e.g. restlessness, poor eating, agitation, insomnia, distress etc.) and an increase in carer burden, or sustained stress and fatigue associated with workload. Subsequently, The ASI National Helpline and Dementia Adviser Service experienced increased volumes of calls from people who were:

- Unable to access their usual supports and services such as social clubs, support groups, day and respite centres.
- Increasingly unable to reach the health and social care professionals that usually support them, for example Public Health Nurses and Dementia Nurse Specialists operating from memory clinics (due to redeployment).

In response to this, The ASI developed a brand new service to support people with dementia and their families who were in need of more help.

2.2 Aims and Implementation of the Dementia Nurse Service

On 20th April 2020, The ASI launched the Dementia Nurse Service, offering 1:1 telephone or video calls with a Dementia Nurse. This created a space for people with dementia and / or their families to discuss and address specific issues that may be arising for them during the COVID-19 pandemic due to the quicker progression of dementia (e.g. changes in behavior, continence management, coping with stress, support escalation to relevant agencies, nutrition etc.) and suspension of face-to-face services.

This service is promoted on The ASI website, through social media and engagement with partners such as the National Dementia Office, HSE at a national and local level, the Alliance of Age Sector NGOs, Dementia Providers Alliance and the Local Government Community Call Helplines, to ensure the service can be highlighted to those who need it.

The Dementia Nurse Service has had 234 call backs with people living with dementia and carers or family members between the 20th April and 14th August 2020.

2.3 Evaluation Objectives

The ASI carried out an evaluation of the impact of this service under the two following aims:

- To explore the experiences of this service from the perspective of those who used it, and to gain insight into the extent to which it meets the needs of people with dementia and their families.
- To gain insight into what benefit, if any, this service provides to people with dementia and their families, and the most important aspects of this service from the perspectives of those who use it.

2.4 Methodology

A survey comprising a mix of open-ended, categorical, and Likert scale questions was developed.

Callers to the service were informed about the surveys after their appointment with the Dementia Nurse. Callers were only informed about the survey if appropriate, i.e. if they were not in distress.

If the caller wished to complete the survey, the Information and Helpline Manager sent an anonymous link to their email address. Alternatively, the caller could choose to complete the survey over the phone with a member of the Research Team. Data were collected between May 15th and July 15th.

2.5 Profile of Respondents

- Fourteen respondents took part in this survey.
- Two opted to complete it over the phone with The ASI Research Officer while the remainder completed it online.
- Unfortunately, the number of respondents is low but not unexpected given the nature of the service. Many callers to the service were typically experiencing some level of distress and contending with a significant caring workload.
- All 14 respondents identified as a family member or a carer of a person with dementia.
- The majority were aged between 40 and 59 years of age and most identified as a son/daughter/adult child of the person with dementia.

Figure 2.1
Relationship to person with dementia

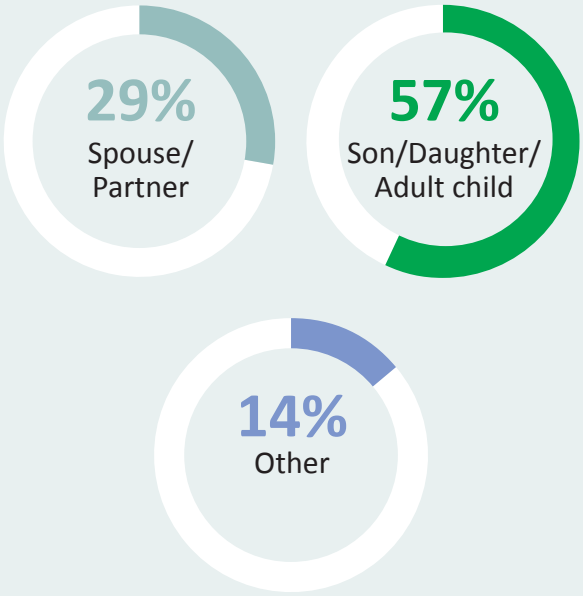
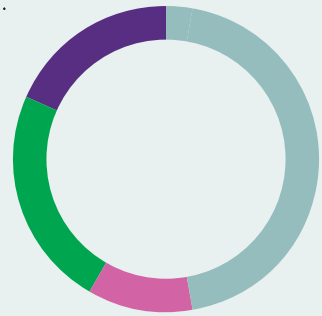


Figure 2.2
Age Range of Participants



69% Ages 40 – 59

15% Ages 60 – 65

8% Ages 66 – 75

8% Ages 75+

The ASI National Helpline referred six of the survey respondents while others found out about the service through other ASI staff members, internet searches or the ASI website.

According to data from the ASI Information Team, the majority of callers to the Dementia Nurse Service had a loved one diagnosed a number of years ago, with 68% having a diagnosis more than two years ago. On the other hand, callers to The ASI National Helpline are generally calling about someone newly diagnosed between six months to two years ago.

2.6 Caller Expectations

Callers' expectations and hopes for how the service might help them centered on (a) receiving expert advice and information and (b) finding support/ reassurance.

> "[I was] Looking for some information and support. I needed someone to understand how difficult I was finding looking after my dad."

> "I was looking for advice from someone who knew more about dealing with dementia than myself as I just felt a little lost."

> "I was very stressed, fearful, struggling, overworked, and I thought they could help me."

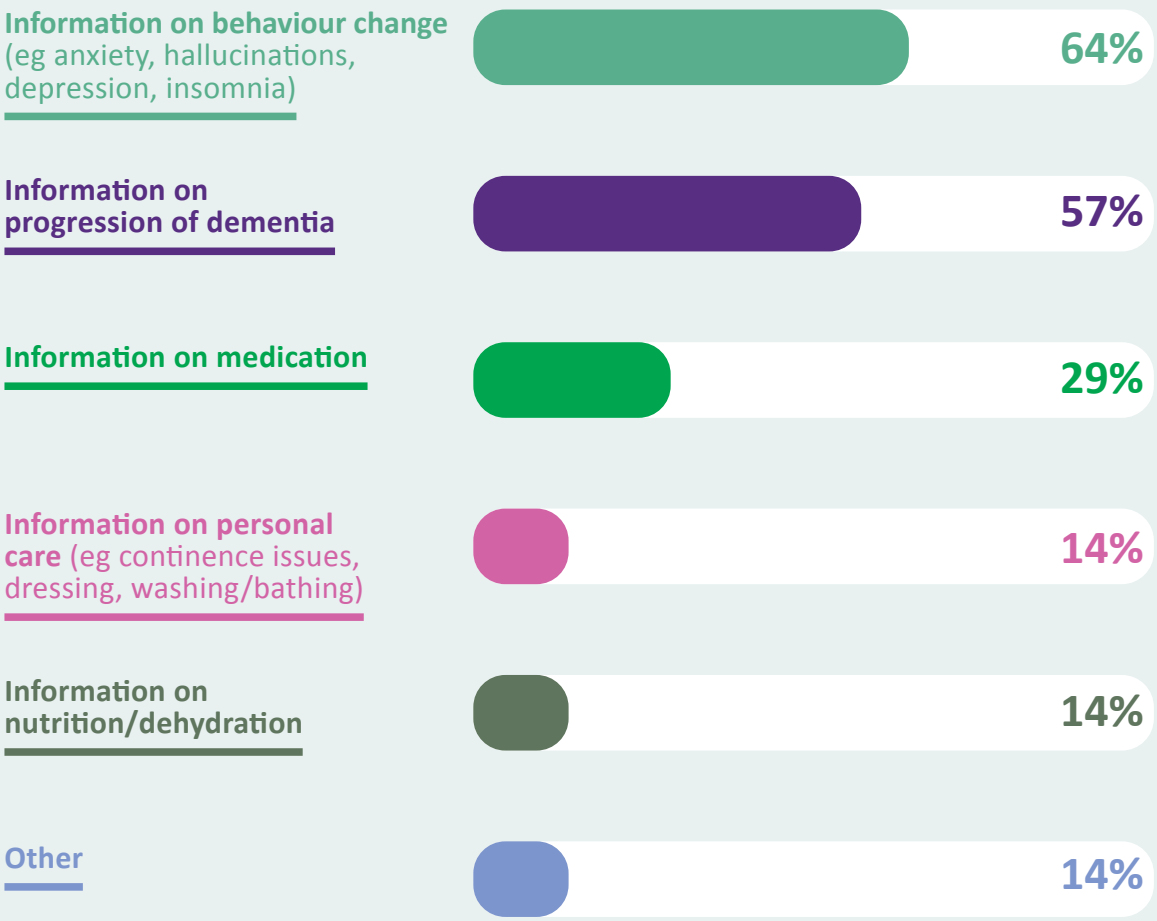
2.7 Reason for Appointment

Of all the calls coming through for the Dementia Nurse Service (n=234), carer stress ,increased isolation, loneliness and struggling to cope came up in over 40% of calls. According to general data from the ASI Information Service, the main reasons for contacting the Dementia Nurse Service included:

- Medication
- Progression of dementia
- Changes in behavior including anxiety, not sleeping, paranoia, aggression and hallucinations
- Information on services and supports available currently including ASI Home Care, HSE Home Care, PHN's and Dementia Advisers
- Activities
- Continence Management
- Diet and Nutrition
- Safety

Survey respondents (n=14) reported contacting the Dementia Nurse Service for more than one reason, most commonly for information on behaviour change and the progression of dementia. We know that many people living with dementia are experiencing a more rapid deterioration of symptoms due to cocooning and COVID-19 restrictions on services. 'Other' responses included '*I was in a very difficult situation*' and '*Information on services/funding*'.

Figure 2.3
Reason for making appointment with Dementia Nurse Service



2.8 Experience of using the Dementia Nurse Service

Figure 2.4
Experience of using the Dementia Nurse Service

Feedback about the service was overwhelmingly positive with all respondents rating it as very helpful. Several respondents mentioned how reassuring and helpful it was to receive a follow-up phone call from the Dementia Nurse they originally spoke with. Most respondents (50%) had two conversations with the Dementia Nurse but some had up to six appointments.

Listening Ear/Reassurance

Respondents felt that the Dementia Nurses provided *'a reassuring and calm listening ear'* and were treated with genuine compassion and kindness. Through speaking with the Dementia Nurses they felt *'completely understood'* and that they could voice their anxieties and worries free of judgement. Respondents also commented that the service felt personal and they had ample time with the Dementia Nurse. They said they did not feel rushed as can sometimes be the case with other healthcare professionals. The ASI Information and Helpline Team report that over 60% of total calls to the Dementia Nurse Service were over 30 minutes in duration.

> "It was the first time I spoke to anyone who really understood and someone who listened. I was at the end of my tether. No one else really understood but the nurse was amazing, and they completely understood."

> They immediately put my mind at ease, confirming what we were going through was completely normal."

> "So understanding, kind, felt I was going mad from stress and they reassured me."

Expert Advice and Recommendations

Respondents valued the level of knowledge and expertise of the Dementia Nurses, and particularly highlighted the practical suggestions and advice they received. This was valued even more so as access to information during COVID-19 became more limited due to redeployment of healthcare staff.

> She listened and gave practical advice and rang back to see if it worked."

> "He helped me gauge where my father is at, gave me very useful information, very understanding too, as it was hard to see the wood from the trees."

> "They made suggestions I wasn't able to think of due to the stress of living with dementia."

Of the 14 respondents, 12 (86%) said that their situation had changed for the better after using the Dementia Nurse Service and in some cases this impact was substantial. Callers had a safe outlet to express anxieties, frustrations and concerns that could then be met with practical advice, guidance and expert information. This has helped to relieve stress and anxiety among most respondents at an extremely challenging time (COVID-19).

After their appointment with the Dementia Nurse Service:

- 90% of respondents felt less anxious than usual,

> Now that we know what we are going through is to be expected, we are far more relaxed."

- 82% of respondents felt more supported than usual,

> It was the first time I felt not alone as I live and care for both elderly parents…I was so busy juggling everything and one day my dad got really bad, I forgot to reach out and one day I did which lifted a lot off my shoulders and most of all to be heard as a person too."

- 92% of respondents felt more equipped with information,

> I've a better understanding of how to manage his care, and what to expect, and how I can plan for future care. It gave me a good sense of what to do next."

- 67% of respondents felt less overwhelmed than usual,

> "I'm in a much better place and look forward to her call, and that she listens. It has had such an impact on me. She has excellent knowledge and I know what to discuss with the GP next. She has made all the difference. No-one else was listening to me and people assumed that I was ok, but I was struggling."

- 73% of respondents felt more hopeful than usual,

> "...I feel more positive about the future."

Respondents were asked about ways in which the service could be improved. Eleven respondents did not have any suggestions. The three remaining respondents suggested:

- Having a Dementia Nurse join a shared family call with other siblings so all family members can learn from them.
- A follow up email with some areas that were discussed (the respondent regretted not taking notes).
- Receiving an email or text reminder after the appointment of how to contact the nurse in the future.

All respondents said they would recommend the Dementia Nurse Service to another person.

Figure 2.5

Percentage of respondents who would recommend the service to another person

2.9 Summary of Key Points

- The Dementia Nurse Service is extremely valuable to the families of people affected by dementia. The feedback was overwhelmingly positive.
- While the number of people who took part in this survey was small, the positive impact of the service is clear.
- Although some services may resume and healthcare staff may return from redeployment, family carers will still need to contend with stresses of COVID-19 and symptoms of dementia that have worsened over the course of this pandemic. At a time filled with stress, anxiety, frustration, and uncertainty, people have been able to turn to this service and were provided not only with specific expert advice, but also compassion, kindness and reassurance.

Section 3

Virtual Cafe Evaluation

3 Virtual Café Evaluation

Before the COVID-19 pandemic, The ASI hosted Alzheimer Café's once per month in different locations across the country. In 2019 alone, The ASI provided 69 Alzheimer Café meetings with 1,928 attendances. They were an opportunity for people living with dementia, their families, and other stakeholders to learn from expert speakers, to socialise and to share knowledge. As with ASI's other face-to-face services, The Alzheimer Cafes were suspended when the COVID19 pandemic struck.

In May 2020, The ASI began piloting Virtual Alzheimer Cafés and offered a country-wide rollout in June 2020.

3.1 Aims and Implementation

The ASI Virtual Café aims to provide a warm and welcoming space online for people with dementia, their family and friends, social and health care professionals to meet and exchange knowledge. The service is based on an international model and held once a month with a guest speaker at each. The speaker discusses a topic of interest and there is an open Q&A session afterwards.

The cafés are hosted through Google Meet (video conference software). The service is promoted to existing contacts and publicised on The ASI website, social media channels and through engagement with partners such as The National Dementia Office, Understand Together, HSE at a national and local level, the Allianz of Age Sector NGO's and the Local Government Community Call Helplines.

Although the cafés are held online and open to the public, they are divided into regions so that people who attended face-to-face cafés (pre-COVID) can meet with their same group if they wish. There were 553 attendances across 32 cafes between 9th June and 8th December 2020.

Speakers include Family Carers, Occupational Therapists, Solicitors, Yoga Instructors, Naturopaths, Professors, Dysphagia Chefs, and Advocacy Experts.

Table 3.1
ASI Dementia Cafes delivered between June and December 8th 2020

Region	Number of Cafes held	Number of Attendances (attendees living with dementia)
Eastern Region	**17**	**322** (1)
Glasnevin	5	86
Louth/Monaghan	5	131 (1)
Dunshaughlin	7	105
North-West/Mid-West Region	**5**	**165**
Galway City	5	165
South East Region	**10**	**66** (3)
Clonmel/Waterford	5	25 (3)
Wexford Town	5	41
Grand Total	**32**	**553** (4)

3.2 Evaluation Aims

- To gain insight into what benefit, if any, this service provides to people with dementia and their families.
- To gain insight into the most important aspects of this service from the perspective of those who use it and whether or not people would attend this service in future.
- To identify areas for improvement in this service.

3.3 Methodology

A survey comprising a mix of open-ended, categorical, and Likert scale questions was developed. This survey could be completed anonymously through an online link or with a member of The ASI Research Team over the phone.

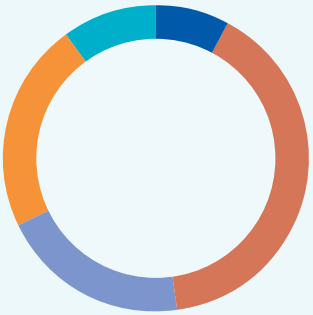
After each café, the organiser distributed the anonymous survey link by email to all who attended. The organiser also distributed the details of The ASI Research Team who could be contacted by any person who wanted to take part over the phone.

Data were collected between May and December 2020.

3.4 Profile of Respondents

A total of 51 people took part in this survey. 53% of respondents identified as family members or informal carers while a quarter were care professionals. 'Other' included former family carers and volunteers. No person living with dementia completed the survey. The vast majority of respondents were over 40 years of age, with 40% being between 40 and 59 years old. Just over half (56%) had attended face-to-face Alzheimer Cafes while 44% were new to Alzheimer Cafes (virtual or otherwise).

Figure ?.
Age range of Respondents



8% Ages 26 – 39

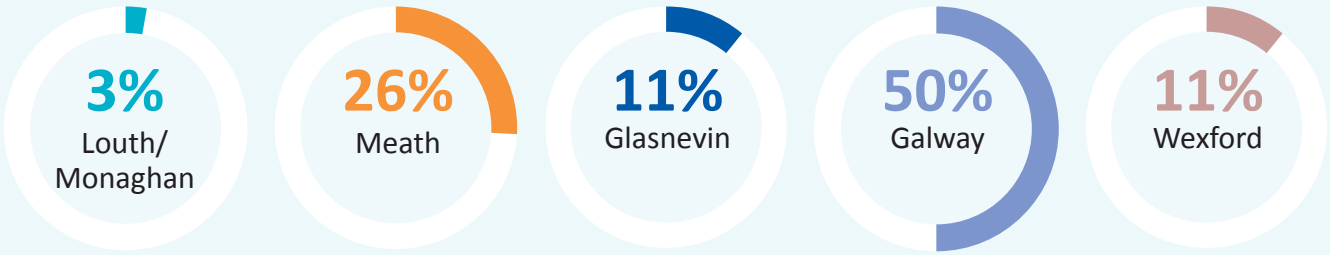
40% Ages 40 – 59

20% Ages 60 – 65

22% Ages 66 – 75

10% Ages 75+

Figure 3.2
Location of café attended



3% Louth/ Monaghan

26% Meath

11% Glasnevin

50% Galway

11% Wexford

3.5 Reasons for Attending the Service

In general, respondents attended the Virtual Café for more than one reason. The most common reasons for logging on were *for advice and information* (36%), *to listen to the speaker* (28%) and *to see what the service was about* (17%). No respondent selected *'a break from caring'* or *'for something to do'.*

Figure 3.4
Why did you log on to this week's Virtual Cafe? (Choice by percentage)

To see what it was about	17%
To socialise with others	5%
For advice and information	36%
I wanted to listen to the speaker	28%
I miss the Alzheimers Cafes I attended before Covid-19	9%
Other	5%
A break from caring	
For something to do	

3.6 Experience of the Service

Attendees were sent a plain-language guide on how to log on to the café. 69% of respondents found the process of logging on to join the café extremely easy while 20% found it somewhat easy. One person felt that logging on was difficult and suggested that a practice session beforehand might be helpful.

We asked respondents what they liked about the service, and what they felt could be changed or improved. The vast majority of respondents were very positive about the Virtual Cafes commenting on the sense of community, learning new information, and enjoying the atmosphere and activities.

- 61% of respondents strongly agreed that it was an hour well spent, while 35% somewhat agreed with this statement.
- 88% of respondents said they would attend another café, while 13% said they might.
- 94% of respondents would recommend the cafés to another person.

One person commented that the Virtual cafe *"is a great way to experience the education, information and socialising that we used to experience when we all met in person at the actual Cafés".*

Sense of Community and Social Atmosphere

A sense of community can be challenging to emulate within a digital environment and just 5% of respondents logged on to the Virtual café for the purposes of socialising. However, the majority of respondents mentioned the sense of community and the *relaxed, friendly*, and *welcoming* atmosphere at the cafes. This was particularly apparent in data collected later in 2020, perhaps due to continued social isolation due to COVID 19 or as attendees became more familiar with each other and the format. A number of people also mentioned the *friendly and caring attitude* of the café facilitators.

> "I just really appreciated the opportunity to connect with other people going through the same thing as me. Sometimes it can be such a lonely place to be and you can go down a dark hole of despair but the laughter and sense of community on the call (as well as the singing!) was such a lovely thing to experience."

> "It offered an opportunity to connect with people that we have been unable to connect with in person due to Covid-19."

> "I felt like I was part of a community."

Advice, Information and Speaker Expertise

The majority of respondents also commented on the high quality of speakers and felt they learned a great deal from them. They valued the *expertise* and *professionalism* of speakers and felt their advice was *practical, very well presented* and *easy to listen to.*

- 57% of respondents agreed that they learned something new from the guest speaker. 71% of respondents *strongly agreed* that they learned something useful from the guest speaker while 25% *somewhat agreed.*
- 61% of respondents agree that they feel more equipped to care for somebody with dementia after attending the cafés (29% strongly agree, 32% somewhat agree). 35% selected neither agree nor disagree.
- 15% of respondents agreed that they felt a little overwhelmed with information at times.

> "The speaker was a good choice for the first café. His experience was relevant to people who are on the same journey."

> "Very interesting and nice to see everyone's faces and see what they were doing. I learned alot from the speaker."

Enjoyable Activities

Several respondents mentioned that both they and their loved one enjoyed the activities at the cafes such as singing and viewing art.

> "I find the speakers interesting and my Mam loves listening to the music and one of the Ladies has a lovely Galway accent and Mam loves to hear it. It makes her smile."

> "I have a background in being very interested in Art. On the day I attended I was exposed to the very progressive work being done within the Irish Modern Art Museum to include people experiencing dementia, their carers & interested others in the Museum & Art."

> "[I particularly liked] the sing song and presentation slides."

Areas of Improvement

Suggestions included recording each café as those working regular hours cannot attend the cafes. A small number of respondents mentioned that they would enjoy more interaction and input from attendees. For example, one person felt that they *didn't see people other than staff.*

No person with dementia took part in the current survey. However, one family carer commented that her husband really enjoyed the face-to-face Alzheimer Cafés but he finds the virtual ones exhausting. Therefore, it would be important in any future research or monitoring of this service to ascertain if people with dementia are attending, and gaining any benefit from the service. Perhaps this service could include a shortened version specifically for people with dementia who might struggle with viewing a screen.

3.7 Summary

- The Virtual Alzheimer Café is a valuable service providing information and a sense of community to carers of people living with dementia across Ireland.
- While digital environments cannot replace face-to-face services, the Virtual Cafés are currently providing a welcome, positive and supportive space for family carers to meet and learn from experts.
- Data from over 50 respondents clearly depicts the value placed on this service by those who attend it. Attendance at the Virtual Cafes continues to be strong with many attendees logging in regularly.
- 61% of respondents strongly agreed that it was an hour well spent, while 35% somewhat agreed with this statement.
- 88% of respondents said they would attend another café, 94% of respondents would recommend the cafés to another person.
- Additional research is needed to explore the potential of permanent Virtual Alzheimer Café to complement The ASI's face-to-face offering.

Section 4

Online Support Group

4 Online Support Group

The Online Support Group (OSG) aims to provide support to family carers of a loved one with dementia. It has been set up in response to ongoing requests from family carers and also as a response to the Coronavirus (COVID-19) pandemic. It is facilitated by ASI trained tutors and dementia experts. Content is driven by participants and their needs and preferences. Each course lasts for 20 weeks, and attendees are supported to get online with detailed instructions.

The OSG includes a number of elements. These include

- Moderated Discussion Forums where members can post messages that can be seen and responded to by the rest of the group.
- Questionnaires to get an understanding of the needs of attendees so appropriate support can be given.
- Weekly Video Meetings with a facilitator from The ASI.
- Activities aimed at promoting discussion and interaction.

4.2 Evaluation Aims

1. To explore what impact, if any, the OSG has on family carers who attend it.
2. To gain insight into the experience of attendees, the most important aspects of this service and areas to be improved.

4.3 Methodology

Two surveys comprising a mix of open-ended, categorical, and Likert scale questions were developed. A baseline survey was distributed before the OSG started and a follow-up survey was completed after participants had been engaged with the group for four weeks or longer. Any person taking part in the OSG was invited to complete the survey.

This survey could be completed anonymously through an online link or with a member of The ASI Research Team over the phone. All participants opted to complete the survey using the online link.

Data were collected between May and December 2020.

4.4 Baseline Data (before the OSG began)

4.4.1 Profile of Respondents

The baseline survey was completed by 78 people before they started the OSG. 67% were caring for a parent, while 22% were caring for a spouse/ partner. 'Other' responses (12%) were typically other family members such as uncle or Mother-in-law.

There was a relatively even distribution in the time respondents spend caring for their loved one with dementia (Figure 4.1). 86% of respondents had not attended an ASI Carer Support Group previously and the online offering was their first encounter with this service. 89% of respondents felt confident using computers and IT and 90% found it extremely easy or somewhat easy to sign up for the OSG.

Figure 4.1
Time spent caring

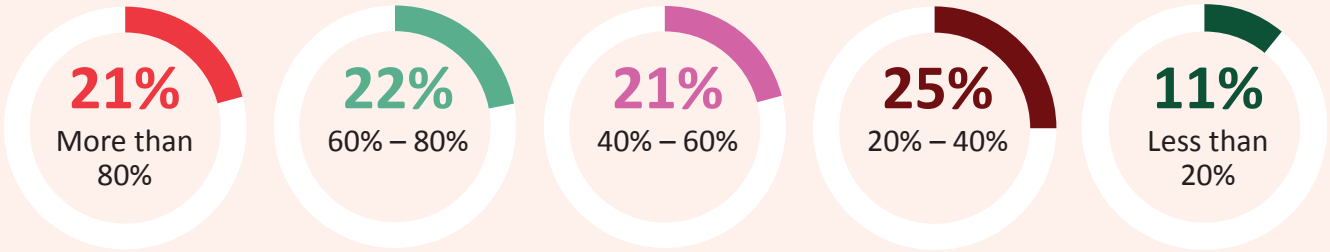
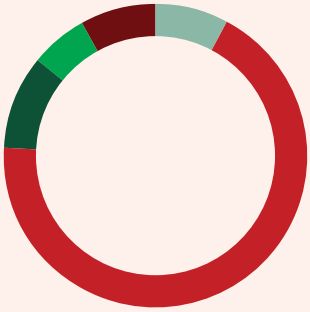
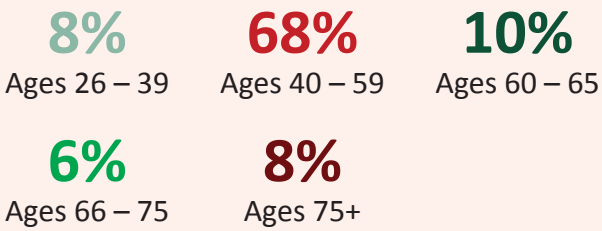


Figure 4.2
Age range of respondents





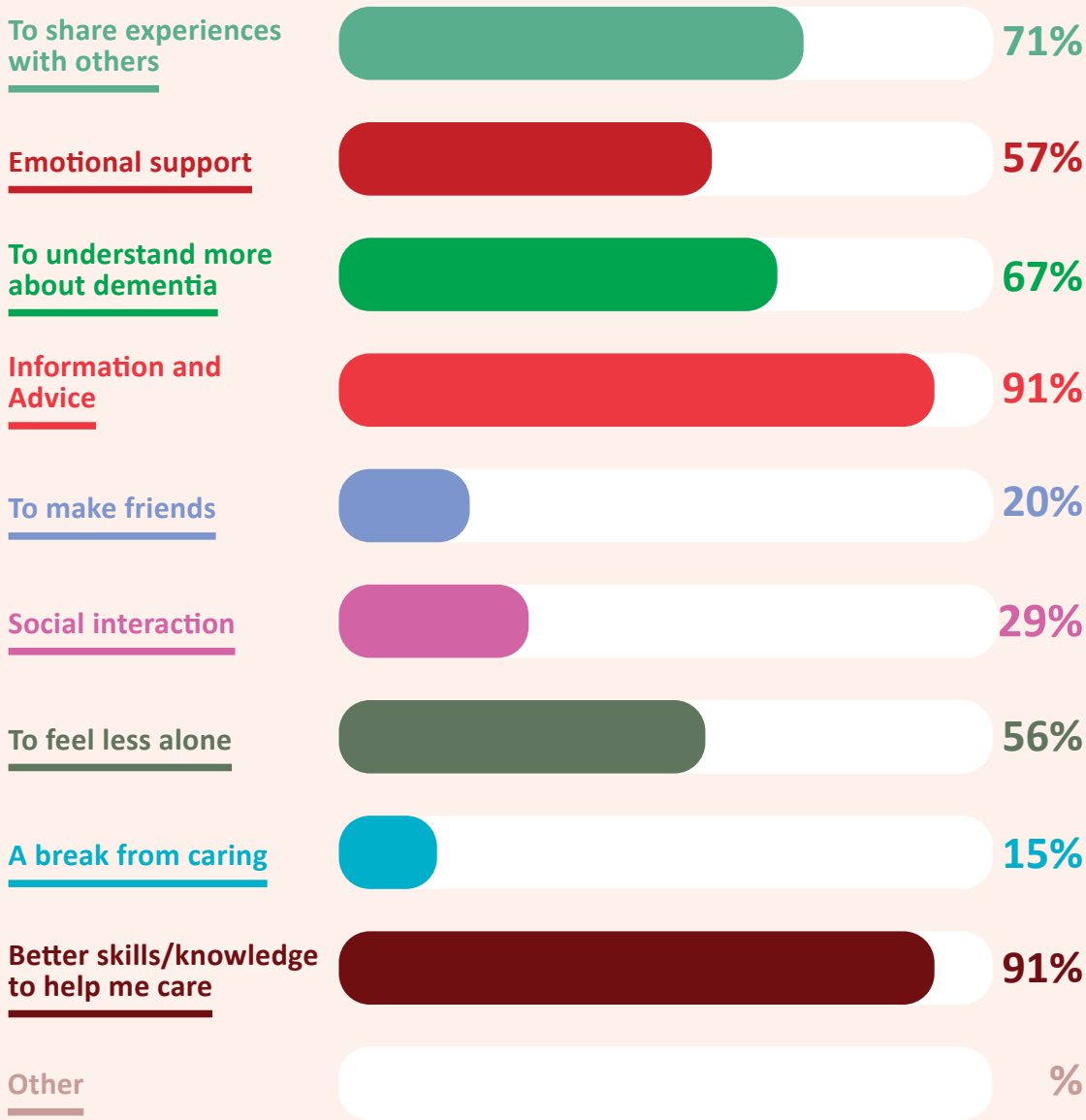
4.4.2 Reasons for Signing Up

We asked respondents why they decided to sign up for the OSG. Out of 76 responses, the most common themes were learning, advice, sharing information, and emotional support. When we asked respondents what they hoped they would get out of the OSG and provided a list of options, the most popular options were very similar.

Figure 4.3
Why respondents decided to sign up for the OSG (free-text)

Figure 4.4

What respondents hope to get from the OSG (% of responses)



Learning, Advice and Sharing Information

Advice, learning and sharing information were key motivators for joining the OSG, particularly as it provided an opportunity to share experiences and meet others in similar situations. Respondents were hoping to get advice on dealing with difficult situations, get a better grasp of resources, practical caring tips,

and find new ideas for activities to do with their loved one. When we asked respondents to select what they hope to get out of attending the OSG,

- 71% selected *'to share experiences with others'*
- 91% selected *'information and advice'*
- 67% selected *'to understand more about dementia'*
- 91% selected *'better skills/knowledge to help me care'*

> "This area is completely new to me. Not sure how to deal with some situations. Am I doing the right thing or not and what should I be aware of. I need all the advice I can get."

> "I am cocooning my mother with dementia now for the last 10 weeks and would love some support for myself too...just want to share ideas on visual aids, photo stories…."

Almost 10% of responses specifically mentioned wanting to be a *'better carer'* and to be able to better support their loved one as the main reason for signing up for the OSG.

> "To improve knowledge and caring skills so that I can help give a better quality of life to my husband."

> "My sister is my Mums primary carer but the rest of the family support her in whatever way we can. These groups enable me to do this to the best of my ability."

Emotional Support

Emotional support was the other most commonly cited motivator for people signing up for the OSG. Some respondents feel out of their depth particularly those whose loved one's dementia is progressing or those contending with a recent diagnosis. Others had benefited from peer-support in other ASI services for family carers (e.g. Family Carer Training) and wanted to continue receiving it. A small number of respondents also mentioned wanting a safe space to be able to speak freely about "*the ups and downs' of caring".*

> "I'm looking for more regular support and circumstances have changed since I did the last course, good to chat to others in similar situations."

> "I am feeling out of my depth on how to react to him."

> I had completed the ASI online course for family carers and found it informative and helpful. I wanted / felt I needed to continue accessing the support."

> "To have contact with people who are in a similar situation as me, to learn more so I can care for my Dad better and to stop me feeling guilty over my emotions and need for space."

Worryingly, a small number of participants wrote about how they are feeling alone, isolated and desperate for help with nowhere else to turn. They find it hard to get out due to their caring responsibilities and COVID-19 restrictions. They hoped the OSG might be an opportunity to meet others who understood them and their experiences. It should be noted that while just six respondents mentioned loneliness and isolation as their motive for signing up in the free-text response, 56% and 57% selected 'to feel less alone' and 'for emotional support' when asked what they hope to get from the OSG respectively.

> "[I signed up] because I feel so alone and isolated. I have no means of communication with someone caring for a loved one living with dementia."

> "I never get a chance to get out so having online support is invaluable. I'm struggling with my mental health at the moment and hope having others for support will help."

Aside from sharing experiences, support and advice with others in the same situations, some respondents also wished to join the group for social interaction (29%), to make friends (20%) and 'to have a break from caring' (15%).

4.5 Follow up Survey

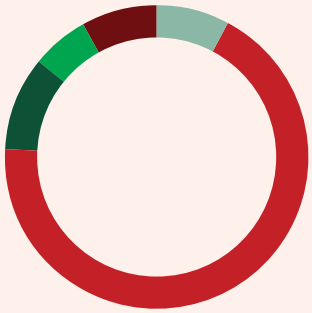
47 people completed the follow-up OSG survey. However, just 31 of these had also completed the baseline survey.

4.5.1 Profile of Respondents (follow-up)

Again, most respondents were in the 40-59 age-bracket. 62% are caring for a parent with dementia while 19% are caring for a spouse or partner.

At the time of completing the survey, most respondents had been involved in the OSG for 17-20 weeks.

Figure 4.5
Age range of participants at follow up



8% Ages 26 – 39
68% Ages 40 – 59
10% Ages 60 – 65
6% Ages 66 – 75
8% Ages 75+

Figure 4.6
Time spent in OSG so far

13% 2 – 4 weeks
17% 5 – 8 weeks
22% 9 – 12 weeks
9% 13 – 16 weeks
39% 17 – 20 weeks

4.5.1 Impact of the service

Respondents were asked if participating in the OSG had changed anything about the way they cared for their loved one.

Figure 4.7

Has participating in the OSG changed anything about the way you care for your loved one?

Those who responded 'yes' were asked to elaborate on how the OSG changed the way they care. Most answers revolved around **having improved understanding** towards the person living with dementia. Following the OSG, participants felt they had **more emotional awareness and insight** into their relative's experience and could react to them and **support them in a better way**. Family carers felt they had become **more patient and compassionate** as a result of undertaking the course. In addition, they learned how to have **better communication** with their loved one and felt more confident in their caring role due to being more educated on dementia. A couple of participants mentioned that they had learned about useful resources or more about their entitlements. Three participants said they were **no longer afraid to ask for help.**

> "I'm more educated now about the illness. I understand the need to ask for help and take breaks. Guilt was a big issue in the past for me."

> "[I have a] better understanding of the illness while helps me to be more considerate and compassionate."

> "My own emotional awareness, I learnt that the person with dementia might forget incidents and events but will remember the emotions so I look for a positive in every situation even if it's just a laugh at ourselves."

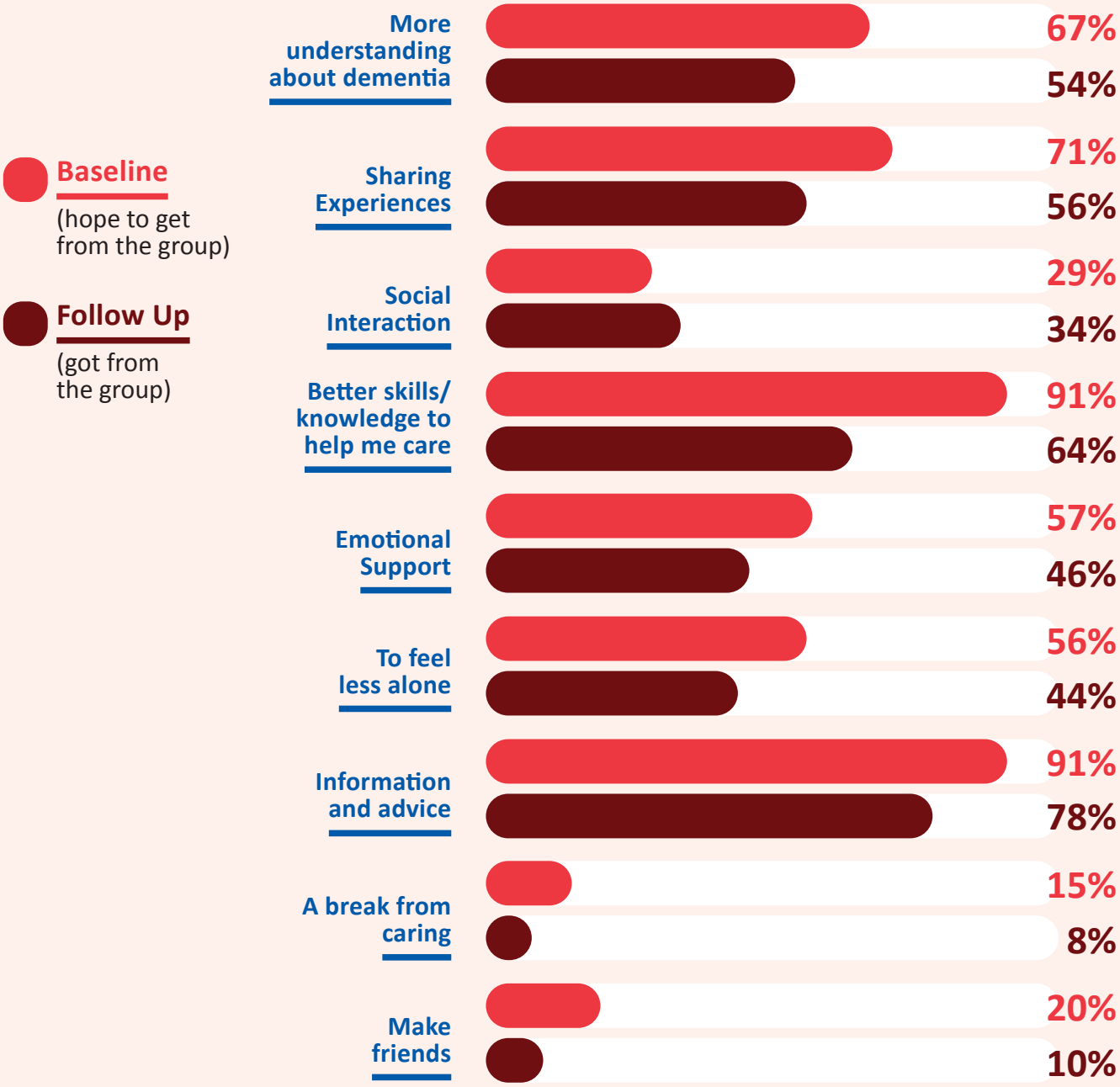
> "[I am now] working at the pace of the person with dementia. I am feeling more confident in my caring role."

> "I am able to communicate better by listening and encouraging my loved one to express her feelings."

As with the baseline survey, we asked what respondents felt they had got from participating in the OSG. Responses in the baseline and follow up surveys are compared below.

Figure 4.8

Baseline expectations and follow-up experiences of the group

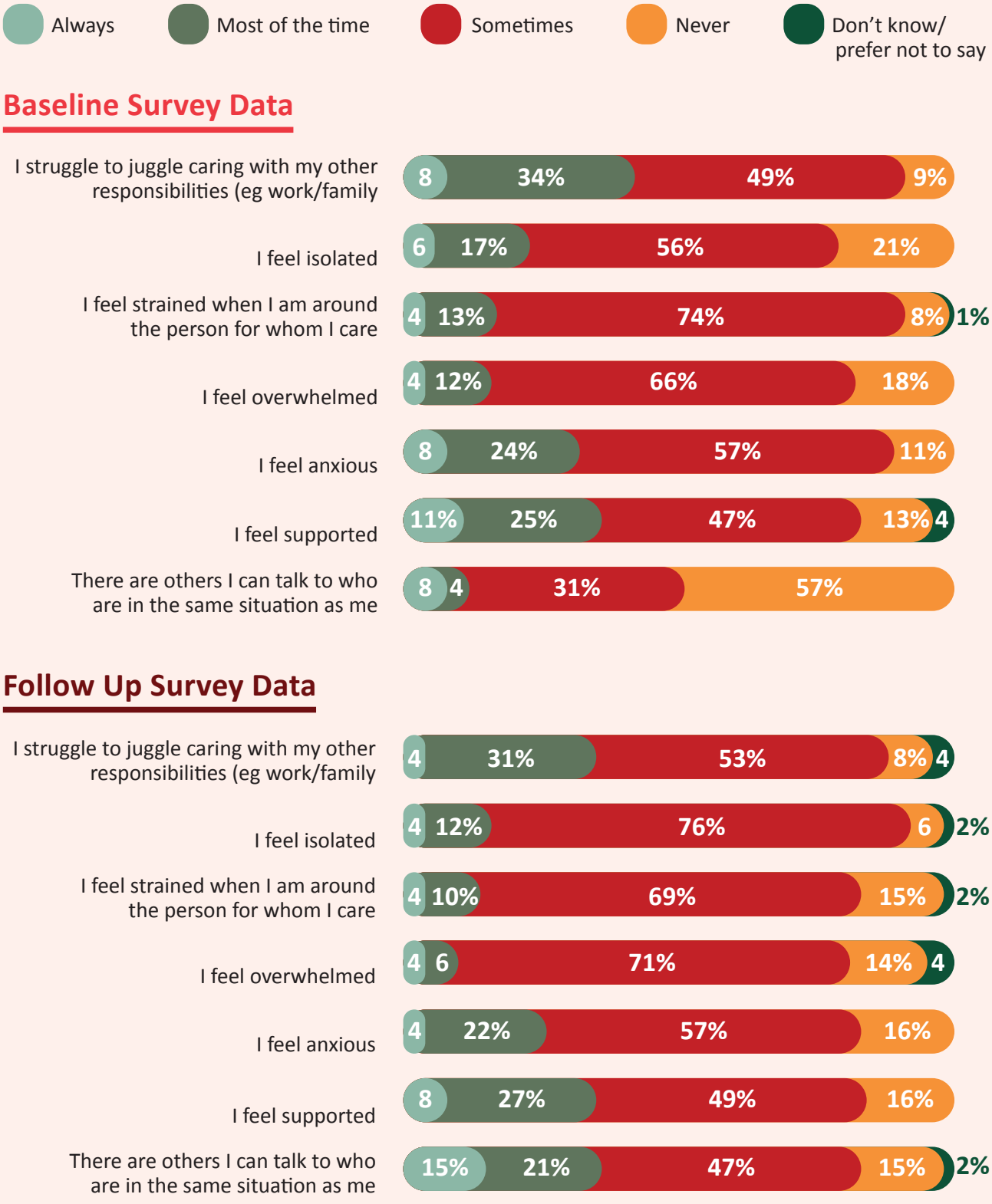


28 respondents answered this question at both baseline and follow-up. We asked these respondents to rate how they were feeling in both the baseline and follow up surveys to understand if the OSG was making an impact in certain areas. While we did not identify any statistically significant differences, we suspect this is partly due to COVID19 restrictions changing, differing times spent in the group and low numbers of respondents completing both baseline and follow up surveys. The below charts depict responses at baseline and follow up timepoints. Percentage values have been normalised.

In general, respondents appeared to feel less strained and spent less time feeling overwhelmed at follow-up compared to baseline. One of the most marked differences is that at baseline, 57% of respondents felt they 'never' had somebody to talk to who was in a similar situation. This was reduced to just 15% at follow up. Of note, feelings of isolation appeared to increase between baseline and follow up which may have been due to ongoing COVID-19 restrictions.

Figure 4.9 & 4.10

How respondents are feeling in relation to caring (baseline & follow up)



4.5.2 Helpful and Liked Aspects of the Service

95% of respondents would like to see the OSG continue in the future. We asked if there is anything attendees particularly like or find helpful about the OSG. 39 respondents provided an answer to this question, and answers generally reflected the motivators for signing up for the group in the first place (Section 4.4.2).

Figure 4.11.
What participants liked/found helpful about the OSG

Respondents valued the interaction with others in similar situations to themselves, and particularly appreciated learning new information and insights from each other in a supportive and understanding environment. Many respondents felt they were getting 'expert advice' from both the facilitators and other members of the group. Two respondents also mentioned feeling good about helping others when they shared information. Some respondents mentioned feeling less alone since they joined the group and felt reassured that there were regular meetings where they could ask questions and receive support. Respondents complimented the facilitators on how they managed emotional aspects of the course and provided a safe space for attendees.

> "The fact that everyone knows what I'm going through. They understand, I don't have to worry about showing my emotional state of mind...it's a comfort to be with likeminded people."

> "Just seeing how other people in similar situations cope and to hear their advice. Also, I'm happy to share my experiences with others so they may feel comforted or that it's of use."

> "It is a lonely road the carer support group takes away some of the aloneness!!"

> "The emotional support - I found by realising others are in the exact same position with the same emotions as me I felt relieved as sometimes I felt guilt for feeling tired or frustrated. Now I'm kinder to myself and as a result a better carer...I think!!"

> "Learning more and getting so much information from the tutors and experiences from other members."

One respondent commented that the course made her feel anxious about the future as her family member was recently diagnosed and she was exposed to discussions around later stages of dementia.

> "…hearing how bad this will get created more fear and anxiety for me. WE are dealing with it day by day and not looking into the future too much and just trying to enjoy my mum and keep her happy and content."

4.6 Suggestions for Improvement

Suggestions on how to improve the service included

- To inform attendees of discussion topics beforehand*
- To allow more silences and space to talk and create an opportunity for everyone to speak
- Reminders in advance of meetings
- More varied times* and being able to switch meeting times
- Simplify the written forums
- To set up a separate group for rare dementia as the caring experiences can be very different
- To have smaller groups as *"the group is too big to facilitate rapport or intimacy"*
- To arrange meet ups when safe to do so
- Consider extending the group past 20 weeks*

Respondents had an opportunity at the end of the survey to add anything they felt was relevant. The vast majority took the opportunity to thank the organisers and facilitators of the OCSG and The ASI for providing the service.

*in more than one response

4.7 Summary of Key Points

- The Online Support Group is a valuable and important service that is providing information, advice, support and an outlet for family carers of people with dementia.
- This service has made a tangible impact on how carers communicate, interact and provide care to their loved one.
- Data from almost 100 family carers clearly shows that this service is needed as family carers are experiencing loneliness, isolation, stress and need support and information.
- 95% of respondents would like to see the OSG continue in the future

Concluding Remarks

Respondents in these evaluations place high value on the new suite of services offered by The ASI. Collectively, the data generated from the four service evaluations provide a rich and nuanced perspective on the role and value of this new suite of services, how the services are operating on the ground and can also inform discussion and decisions about what might be an optimal model of service delivery to strive for within the Organisation. As The ASI gradually develops a focused strategic and operational framework for the re-opening and delivery of its services, there will be a need to explore how this new suite of services can be integrated within this future service delivery framework and how it fits in the wider picture of community-based service structures and supports.

We know that we will have to live with COVID-19, and therefore delivering virtual and phone services will continue to play an important role in minimising risk. It will simultaneously play a role in accessing people who live in rural or remote areas who might find it difficult to link in with dementia services under normal circumstances.

These services were initially implemented as an emergency response to urgent need, and it will be important to further explore the role of these services in the wider care ecosystem as circumstances and needs continue to change in this COVID-19 environment and beyond. Additional research should focus on impacts and outcomes for people with dementia and family, and contribute to the wider international evidence base. This could also include examination of the value for money, including measuring delivery costs against the value of any health/social care related gain achieved.

The evaluations found that family carers and some people with dementia provided a range of ideas and suggestions on how services could be further enhanced. A key challenge going forward is embedding personhood in the delivery of these new services and how to actively listen to the voice of the person with dementia. We must also acknowledge that more time with the person is needed to really elicit their views and wishes; and resource and practical support is required to involve people with dementia on advisory forums or working groups. Ensuring personalisation in our new services will require a particular structure of service delivery involving service staff to senior managers, and taking account of the views of and interacting with the person living with dementia and their family. This should involve listening closely, not relying solely on standardised needs assessments; respecting the uniqueness of the person and their circumstances, not providing a 'one-size-fits-all' response; and one that recognises the person and family as experts in what they need, involving them in co-producing the care they rec

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