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Dementia Dog Project

Evaluating the impact of an assistance dog programme
for people living with dementia in Scotland



Dementia Dog Project
A collaboration between Alzheimer Scotland and Dogs for Good

“This year has had its problems for Henry and myself but with Uno’s help, his gentleness and great nature, we both have come out the winners. So, roll on 2019, it certainly can only get better for us both with Uno by our side.”

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Introducing



Name: Webb
Age: 5 years old



Name: Uno
Age: 5 years old



Name: Willow
Age: 5 years old



Name: Ruby
Age: 3 years old



Name: Hope
Age: 4 years old



Name: Odin
Age: 4 years old



Name: Lenny
Age: 4 years old



Name: Yazz
Age: 3 years old

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Dementia Dog Project

Acknowledgements

Thank you to all the families involved in the Dementia Assistance Dog Programme for kindly sharing your stories and time. Thank you also to the Dementia Dog Project team for your work in supporting the evaluation.

The concept

The concept behind the Dementia Dog Project was developed by third-year students at the Glasgow School of Art. Students were asked to develop an innovative new service area for people living with dementia that was person centred, took account of carers, and included an adaptable solution to support the progression of dementia.

About this report

This report is a summary of the work undertaken on the evaluation of the assistance dog programme for people living with dementia in Scotland. The work was undertaken by The Dementia Centre, HammondCare. You can learn more about us and our research team in the appendices.

We begin with an introduction to the Dementia Dog Project. We then introduce assistance dogs and discuss their role in the lives of people with dementia. This report tells the story of the programme, describing what we have found as we worked closely with the participating families and their dogs, and outlining both the impact of the dogs on the lives of the families they support and recommendations for further consideration and future practice. We have retained the voices of the participants to illustrate the points made, where possible, in order that this evaluation captures the authentic, personal aspects of living life with dementia.

Summary of findings

The Dementia Assistance Dog Programme provides specially trained assistance dogs to people in Scotland who are living at home, where one person has an early stage diagnosis of dementia and another is a full time unpaid carer. Funding from the Life Changes Trust was used to train and provide eight dementia assistance dogs for people in Scotland.

This evaluation considered how assistance dogs can support people to live well with dementia, with a focus on the wellbeing and physical activity of both the person living with dementia and the unpaid carer. The information collected was also explored to ask how an assistance dog might support individual self-management, resilience or better coping, and how people living with dementia may be enabled to realise their citizenship roles within domestic, social and community settings. We found evidence of the significant impact of assistance dogs in the lives of people living with dementia and unpaid carers.

Carers of people living with dementia can experience stress as a result of the unpredicted and unwilling consequences of dementia, changing roles and relationships. Assistance dogs provide a constant resource, for both the person with dementia and unpaid carer, and in doing so promote continuity in people's lives as they adjust to life changes, needs and support. The dogs represent a high cost resource, however, they provide a key role in promoting resilience and citizenship, despite these challenges, in a way that is arguably unmatched by other current service options in Scotland at this time.

Positive impact areas of assistance dogs in the lives of people living with dementia and their unpaid carers.



The carer experience



Dog as a social bridge



Domestic co-production



Togetherness



Dog as a point of continuity



Dog as a public symbol



Physical activity

Dementia Dog Project

The Dementia Dog Project is a charitable collaboration between Alzheimer Scotland and Dogs for Good. Based in Scotland, the project aims to explore and measure ways in which trained dogs can help people to live well with dementia.

Dementia Dog Project

The project is currently in its second phase, having been relaunched in Scotland in August 2016 with funding from the Life Changes Trust. The first phase (2012-2015) involved the training and placement of four assistance dogs with four couples living with dementia at home in Angus, Scotland. The second phase – the Dementia Assistance Dog Programme – is a three-year programme to train and place eight assistance dogs with people living with dementia in the Scottish community from 2016-2019.

The concept behind the Dementia Dog Project was developed by third-year students at the Glasgow School of Art. Students were asked to develop an innovative new service area for people living with dementia that was person centred, took account of carers, and included an adaptable solution to support the progression of dementia. The Dementia Dog concept received funding from the Design Council (2011) and Department of Health via the Living Well with Dementia Challenge (2011), with more funding received in 2012 from the Scottish Government.



What is an assistance dog?

Dementia assistance dogs start their career at just eight weeks old, at the Dogs for Good national training base in Banbury, Oxfordshire. Each assistance dog spends the next two years learning life-changing skills, starting with basic obedience and socialisation during its first year, progressing to more complex and dementia-specific tasks during the second year. The dog is then matched and placed with a family.

Dog selection is guided by temperament and personality, as ultimately it is important that the dog is enjoying its 'job' when it has its working jacket on. For the Dementia Dog Project, ideal dogs tend to be those with a gentle and loving temperament, whose keenness to undertake physical tasks is balanced with a calm nature and a love of being close to people. Alongside this, it is important that the dogs are able to work in a high distraction environment, walking gently on a lead and not being overly boisterous. So, it is a special blend of skills and temperament that makes a great dementia assistance dog.

One of the key benefits offered through the assistance dog programme is the full support provided to families, both through the legal public access rights that qualified assistance dogs are afforded, and the wider holistic support open to families through the specialist team. Unlike pet dogs, assistance dogs can legally access all public places with the exception of operating theatres and food preparation areas, meaning they are able to provide reassurance and support in busy, unfamiliar environments too.

All the dementia assistance dogs receive similar training, however, once a match is identified between a family and dog, the team undertake many visits to that family to build an accurate insight into their individual needs, daily routine and the types of environment they might visit in the community. This is then mirrored into a highly tailored training programme for each dog, to ensure the project is meeting each family's needs in a meaningful and person-centred way. Paramount to this is the overall aim to create a happy and trusting bond between the dog and recipient family to result in a long-lasting partnership.



The role of dementia assistance dogs

As is common with all assistance dog work, considerable effort goes into matching the right dog with the right couple. This goes beyond matching the dog's skills with the support required by the couple and aims in addition to ensure a happy bond is established to form a lasting partnership. When a dog has been matched to a suitable couple, the Dementia Dog Instructor then tailors the dog's advanced skills to meet the individual needs of both the person with dementia and the unpaid carer.

Dementia assistance dogs are trained to help maintain a structured routine at home (Fig.1), to be a social connector within the community and to be an emotional 'anchor' for both the person with dementia and their unpaid carer. Each dog learns skills specific to helping someone with dementia at home, in order to support the emotional wellbeing of both the person living with dementia and unpaid carer, through increased confidence, self-esteem, sense of purpose, and carer resilience.

Helping to maintain a routine

Responding to an alarm, a dog can be trained to retrieve a medication pouch or water bottle to a person's lap to remind them to take their medicine or to hydrate. The dog can learn how to help regulate sleeping patterns, waking someone up in the morning to get out of bed, gently nudging the person awake if he or she naps during the day, and helping to remove items of clothing when it is time to get dressed/undressed. A dog can support 'physical anchoring', i.e. for short periods of time, a dog is trained to stay in one location with the person with dementia, e.g. to allow a unpaid carer to go to the toilet in a café, or do some brief shopping in a supermarket.

Social connector

The dog can retrieve shoes and its lead when it is time to go for a walk, with a dog harness and dual lead (which requires specialised training for the dog and clients) enabling both the person with dementia and carer to take the dog for a walk together. Dogs act as a natural social icebreaker and may provide an opportunity for conversation and interaction within the community. An assistance dog is well socialised to be friendly and gentle when meeting other people and dogs, it walks gently and calmly on a lead, and stays focused on its owner in a high distraction environment. This is where most of the focus rests within the training programme for an assistance dog: to ensure it is consistently calm, gentle and friendly when out and about.

Emotional anchoring

The specific emotional task the dog is taught is a 'head rest', where the dog rests its head in a person's lap and makes eye contact to help ground the person. This can help to reduce separation anxiety, diffuse tension, and help a person feel calmer.

How assistance dogs can help

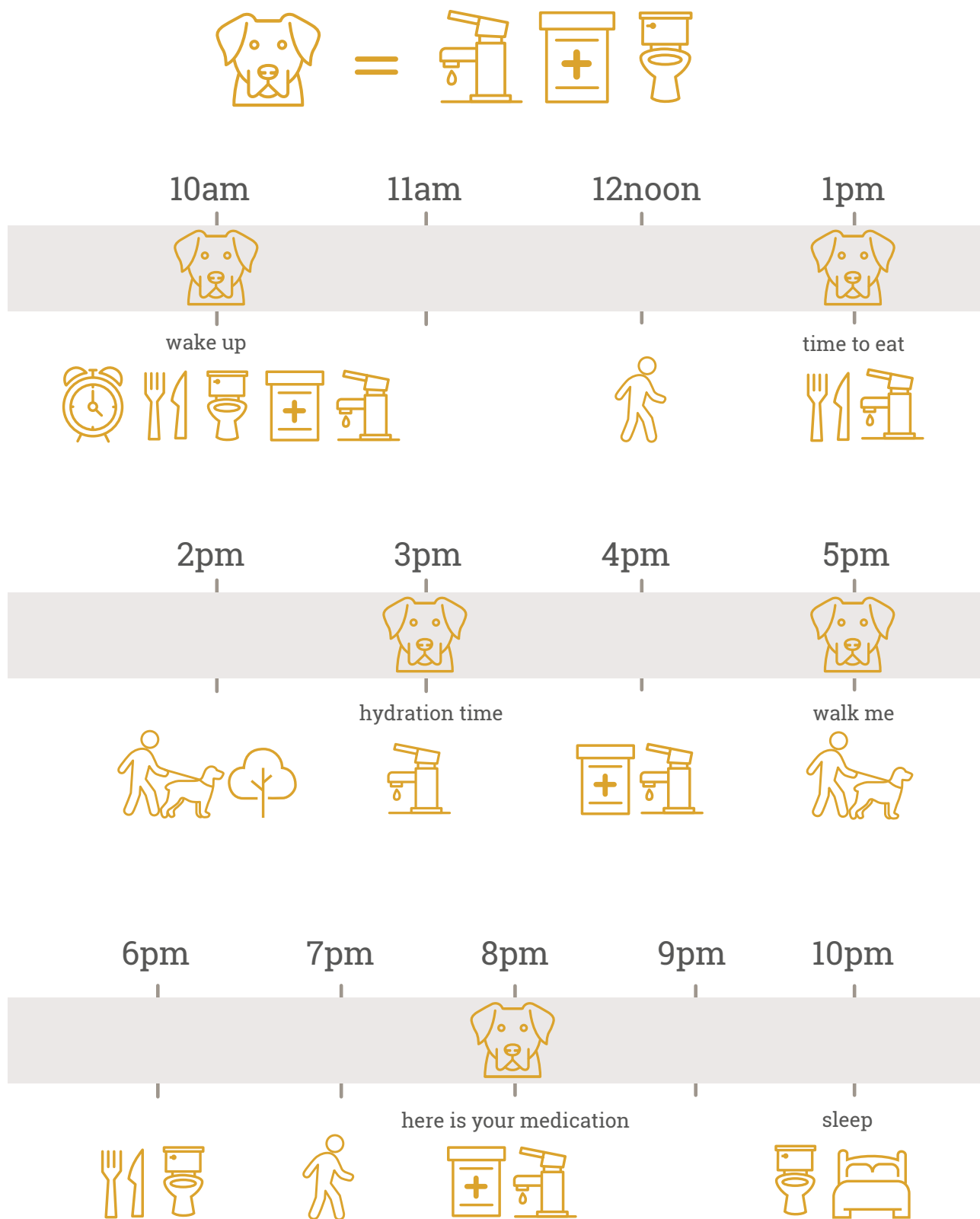
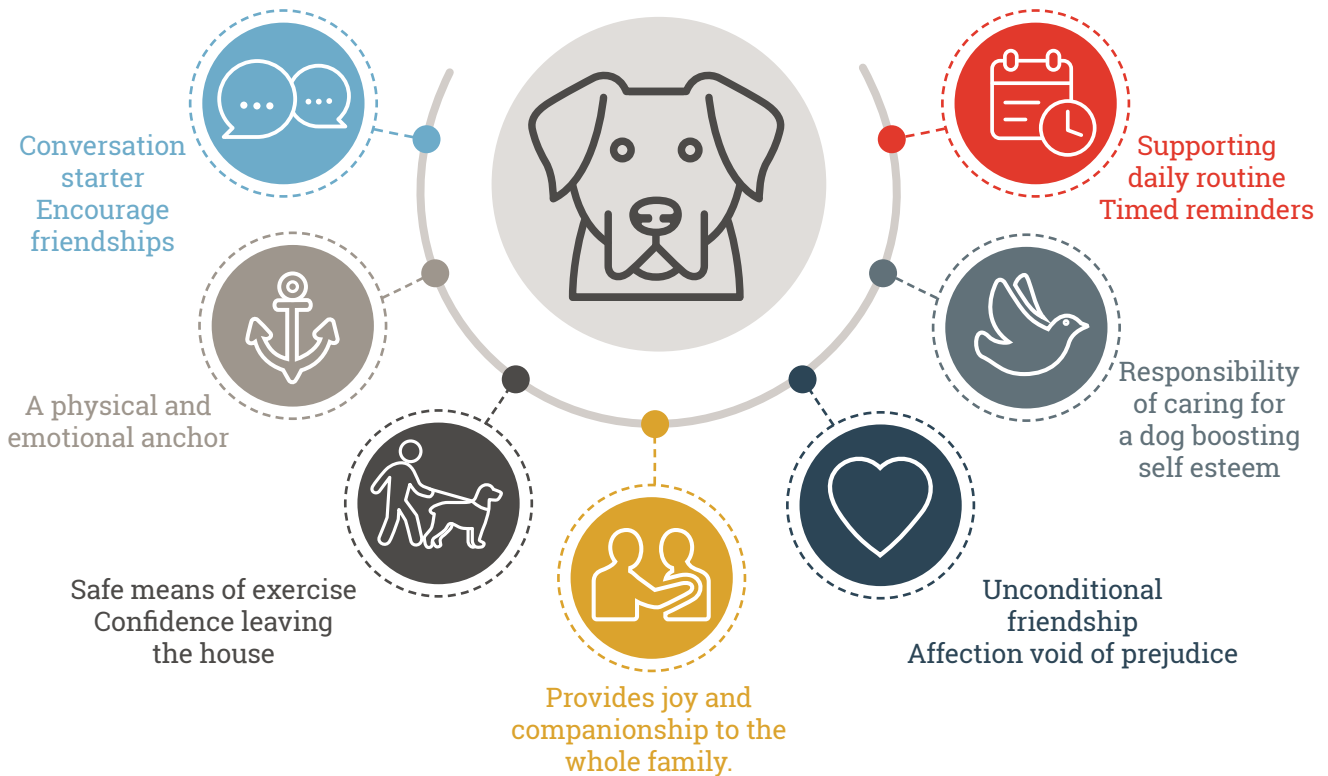


Figure 1. How an assistance dog can help to restructure routine within the home.

The expected benefits



Social interaction

Dogs can act as a bridge to local communities – encouraging conversation and friendship that does not rely on memory. Focusing on the dog can help friends old and new start and maintain relationships with someone with dementia.



Family/carer support

The role of the carer is often lonely and stressful, dogs can provide joy and companionship to the whole family.



Emotional benefits

Dementia can be a very lonely and frightening experience. Dogs are loyal companions void of any human prejudice providing 24/7 comfort and reassurance.



Anchoring

For a person with dementia, dogs can act as a physical anchor: allowing a carer to focus elsewhere, and an emotional anchor: helping one feel safe when alone.



Independence

The responsibility of caring for a dog may boost a person's self-esteem.



Out & about

Dementia can lead to isolation through lack of confidence in leaving one's house. Walking with a dog provides a companion who can reassure and a means of exercise that feels safe.



Routine & reminders

Routine can become difficult for those with dementia. Dogs are creatures of habit and can be trained to support daily routine, responding to timed alarms to remind owners of essential daily tasks.

Peter, Veryan and Ruby's story

Ruby is a female black Labrador who was born on 1st February 2017. A clever and talented girl, Ruby proved herself to be a fast learner with a sparkling personality to match!

Peter was diagnosed with dementia in 2016 and admits it was initially a 'hammer blow' for him and his wife, Veryan. Ruby was matched and placed with Peter and Veryan in December 2018 and quickly became a member of the family. She has bonded closely with her new family and puts her skills to use every day.

There were several considerations for the team to ensure that this was a successful match – not least Ruby's affectionate nature and clever ability for learning new tasks. The team also needed to consider the ability of the dog to cope in varying busy, urban environments and modes of transport to support Peter in attending his Scottish Dementia Working Group meetings, as well as settling easily living alongside the feline members of the household.

Ruby provides practical assistance to the family: she fetches Peter's medication and is an alarm clock that is welcomed with open arms, supporting a positive start to the day and initiating daily routine. Ruby diffuses

tension within the household when things are difficult, using her 'head resting' training to provide a sense of calm for both Peter and Veryan. The family practices other tasks with Ruby for when they may be needed later on.

But Ruby's role in the household is much more than task-based, and very much centres around being the family's emotional 'rock'. For Peter, she is motivator, confidence builder and companion, ensuring Peter remains connected within his local community and can participate in social and civic life. On days when Peter might be inclined to withdraw, Ruby is the incentive to get out-and-about, providing a focus and reassurance that minimises anxiety. In this way, she also assumes the role of personal trainer, as Peter is supported to continue his life-long habit of walking.

For Veryan, Ruby is counsellor and confidante, and ensures that Veryan gets outdoors every day. Walking is restorative for Veryan, and Ruby is an honorary member of the local walking group. She provides a much-needed constant for Veryan throughout a time of shifting sands. In Veryan's words, 'I really can't imagine life without her and our lives would be a lot darker.'

'I really can't imagine life without her and our lives would be a lot darker.'



Peter and Veryan with Ruby

Dementia Assistance Dog Programme

The Dementia Assistance Dog Programme provides specially trained assistance dogs to people in Scotland who are still living at home, where one person has an early stage diagnosis of dementia and another is a full time unpaid carer. Funding from the Life Changes Trust is being used to train and provide eight dementia assistance dogs for people in Scotland.

Dementia assistance dogs come from the charity Dogs for Good and complete around two years of training. Training is initially completed with volunteer socialisers and trainers at Dogs for Good in England, before the dogs move on to the Scottish base for advanced training. This second-stage training is completed in collaboration with the Scottish Prison Service (SPS) and Paws for Progress CIC, as part of Scotland's first prison-based assistance dog training programme. Based at HMP Castle Huntly open prison, this innovative partnership provides an operational base for the Dementia Dog Project team, while enabling men in custody (referred to as 'students') to develop

employability skills and build a non-criminal identity to help reduce risks of future re-offending. A total of seventeen students completed an introductory dog training and welfare course run by Paws for Progress CIC. Fifteen of these students then progressed to support the on-site Dementia Dog Project team, acquiring dog training and team learning skills to help train the dementia assistance dogs in more complex tasks. Paws for Progress CIC are leading on a separate study to evaluate the longer term social and employability benefits for participating students, resulting from their involvement in the prison-based assistance dog training programme.



Dementia Dog Project Team

Dementia Dog Team: Blending dementia and dog specialist support

In all areas of work delivery, the dementia dog strives to provide highly tailored, meaningful and timely support for the families with a dementia assistance dog. As such, the team works closely together, blending specialist dog and dementia skills to ensure a truly holistic approach and to

build a strong bond of trust with each family. In doing so, the team works with the families to anticipate potential challenges ahead, with the aim of avoiding crisis points and ultimately maximising the special partnership each family can enjoy with their dementia dog.

A day in the life of Nadia and Kerry

The Dementia Dog Instructor (Kerry Gough) and Dementia Specialist (Nadia Sutherland) together undertake home assessment visits to applicant families, exploring their motivation of enquiry and expectations of having a dementia assistance dog. Face-to-face visits allow them to capture valuable insights into daily living patterns and routine, as well as some of the difficulties they may be facing with the diagnosis.

Conducting the visit at the applicants' home allows Kerry to assess the suitability of the home for a potential dog, while Nadia is able to identify any dementia-specific needs not currently being met either through formal or informal support networks. From both a dementia and a dog perspective, what suggested supports and interventions could assist in a successful, safe and happy partnership with their dementia assistance dog?

Kerry takes careful consideration of the needs, routine and requirements of the applicant, alongside the qualities and abilities of available dogs, to ensure a good match is made. Once the dog is placed in the home, Kerry commences full training support for the family, covering all aspects of dog training and care, to ensure a happy and lasting bond is established with the couple feeling confident with their dog in different environments.

Meanwhile, Nadia will assist the family to ensure they are accessing all available local dementia support. This could range from signposting to Alzheimer Scotland/ third party/statutory services, applying for blue badge, referrals for occupational therapists or physiotherapists to ensure the home remains a safe place, or creating bespoke volunteer befriender roles to support clients in maintaining their independence with their dementia assistance dogs, while offering respite for their carers.

Nadia works closely with the Digital team within Alzheimer Scotland resulting in families being offered free specialist advice, incorporating technology aids to promote independence and reassurance, and one family having their home future-proofed to support with some of the difficulties that future cognitive and physical decline could present.

Additionally, Nadia has helped families navigate through health and social care to help them access self-directed support, informing families of their rights and supporting them in having the confidence and knowledge to make informed choices about future support. This has led to some of the families now having a budget that allows them flexibility and control over their planned support choices.

Kerry continues regular aftercare visits once dogs are placed with families to ensure that the dog's skills and training continue to support the family as their needs change alongside progression of dementia.

Both Kerry and Nadia feel privileged to experience and share the joy and personal milestones with each dementia dog family. Observing such huge positive change, as well as the dog bringing families back together and helping people come to terms with a diagnosis of their loved one.



Ruby

Learning from previous evaluations

Before the current Dementia Assistance Dog Programme in Scotland, two other dementia dog projects were completed – one in Scotland and one in Australia. Table 1 summarises the evaluation findings of each of these

projects. This information has helped to shape the evaluation of the current programme as discussed in the section that follows.

Finding	Dementia Dog (Scotland)	Dogs 4 Dementia (Australia)
Activity Levels	Increased activity for carer No increased activity for person living with dementia	Increased activity for carer and person living with dementia
Independence, Support & Quality of Life	Living at home for longer Remaining independent for longer Reduced crisis support interventions Support with new tasks as the dementia progresses	Increased confidence for person living with dementia to socialise Increased confidence for carer to have independent time away from home
Carer Support & Carer Burden	Reduced carer stress	Reduction of carer burden
Emotional Support	Emotional support through unconditional companionship and affection for carer and person living with dementia	Improved emotional well-being for person living with dementia and their carer. The assistance dog provided comfort and joy
Safety	Emotional anchoring provided by the assistance dog supports the person living with dementia to feel safe	Assistance dog can evoke greater feelings of safety for the person living with dementia
Socialising	Person living with dementia remained or became more sociable	Person living with dementia remained or became more sociable Person living with dementia had increased confidence to engage in social activities Increased socialising for the carer
Maintained Benefits	Benefits did not diminish as dementia progressed	Assistance dog continues to provide emotional support to family and support network even when dementia has severely progressed
Emotional & Social Benefits vs. Task Based Support	Emotional and social benefits of greater value than task based support	Task based support not utilised as much as initially thought Assistance dog provided much more emotional and social benefits

More detail about the previous evaluations can be found in our interim report on this programme:
<http://dementiadog.org/wp-content/uploads/2019/01/Dementia-Assistance-Dog-Programme-Evaluation-Interim-Report-2018-Web-version.pdf>

Developing an evaluation framework

The findings from both the Dementia Dog Project and Dogs 4 Dementia project were used to develop an evaluation framework for the second phase of the Dementia Assistance Dog Programme in Scotland. It was anticipated that eight fully trained assistance dogs would be placed with eight participating couples living in the community.

The findings from both the Dementia Dog Project and Dogs 4 Dementia project were used to develop an evaluation framework for the second phase of the Dementia Assistance Dog Programme in Scotland. It was anticipated that eight fully trained assistance dogs would be placed with eight participating couples living in the community. The evaluation aimed to explore and measure how assistance dogs can help people to live well with dementia. Data was collected before a dog's placement and at multiple time points thereafter (1, 3, 6, 9 and 12 months following placement).

Following learning from the two previous projects, the evaluation team was careful to limit carer burden during the data collection process and chose a selective number of assessments and data collection techniques. The assessment focus was on measuring reported carer experiences and carer burden, service use and physical activity, whilst qualitative data was collected through journals, video recordings and follow-up interviews in order to retain the voice of the person with dementia and the carer within the process. This evaluation also captured the care and support plans built around the couples, and considered the type and cost of services used by participating couples alongside the assistance dog. Please refer to Appendix Two for the complete evaluation schedule.

The overall aim of the project was to evaluate how assistance dogs can support people to live well with dementia, with a focus on the wellbeing and physical activity of both the person living with dementia and the unpaid carer. The data collected was also used to address how an assistance dog might support

individual self-management, resilience or better coping and how people living with dementia may be enabled to realise their citizenship roles within domestic, social and community settings. This component of the project reflects the current Scottish dementia policy context and contributes to the demand for new models of community dementia care. The evaluation sought to draw out the benefits and challenges associated with the project to ensure a balanced and holistic view and to enable future projects to successfully develop the concept.

Since the development of this approach, Marks and McVilly (2020) have undertaken a systematic review of the research into trained assistance dogs for people living with dementia. They concluded that the current evidence base is inconsistent and recommended that: new studies focus on an adequate sample size as opposed to single case studies; the dogs are placed with families on a full-time basis; the programme runs over an extended period of at least one year; carefully selected measures are undertaken as a baseline and over the course of the programme; and the impact on the wider family and not just the person with dementia is included. This evaluation has clearly met these recommended quality indicators.

Dog placements

Within the Dementia Assistance Dog Programme, eleven couples have had dogs placed with them, six of which are active (continuing) placements. The status of each couple is detailed in Table 2. Two placements ended due to ill health of the unpaid carer, two ended due to unpaid carer stress, and one ended due to a lack of bonding between the person with dementia and the dog.

A total of eight dogs were fully trained as part of the programme. Two of these dogs were retired from the programme due to changes in their behaviour related to stress in the home environment. These dogs were both successfully re-homed permanently with loving families, and are no longer in a working dog role. We return to this later in the report.



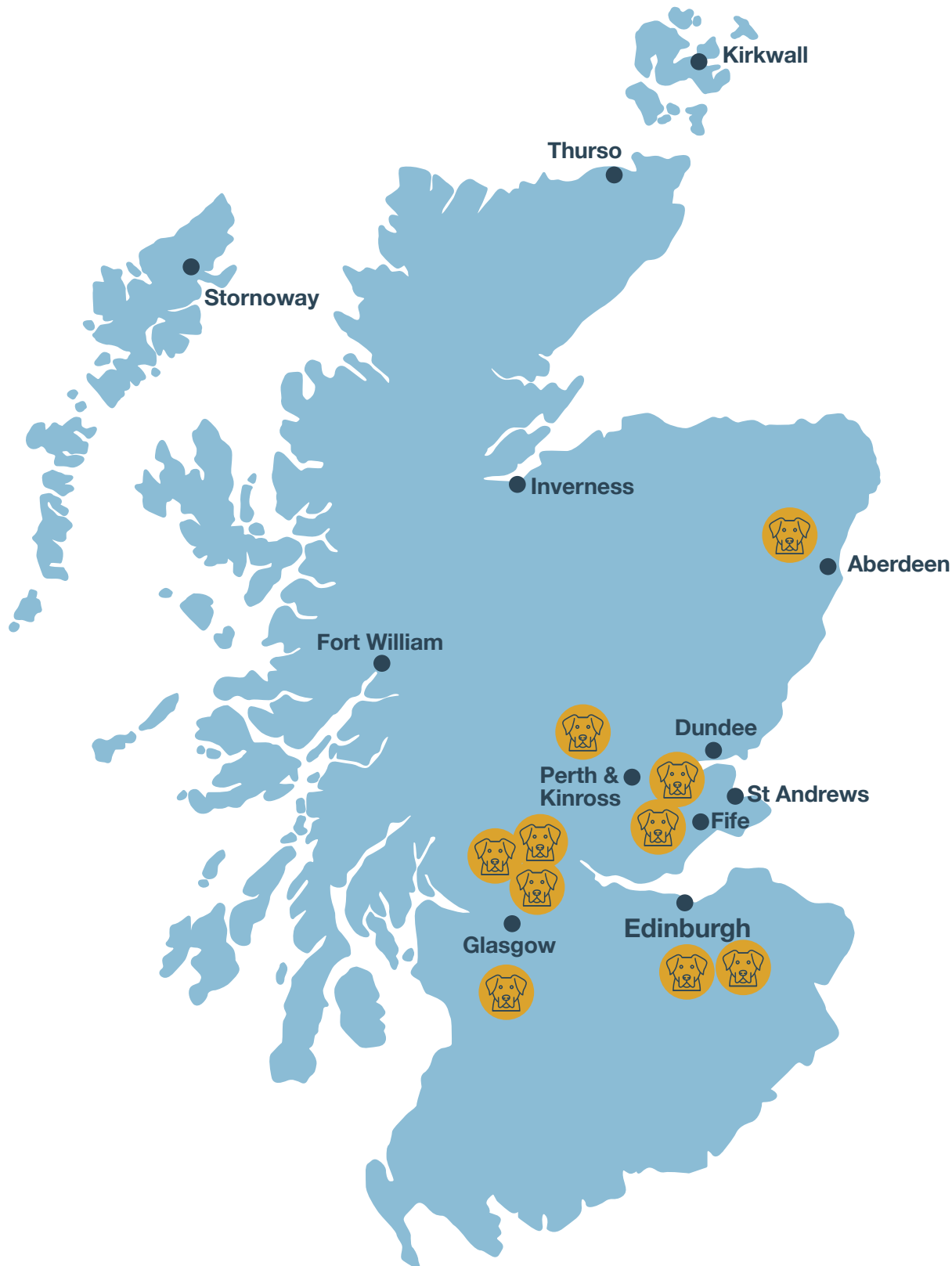
Peter and Veryan with Ruby

Table 2. Placements within the current Dementia Assistance Dog Programme.

Couple	Area	Dog placed	Placement date	Status
Couple 1	Perth & Kinross	Dog A	14 June 2017	Placement ended
Couple 2	Fife	Dog B	28 August 2017	Active
Couple 3	Dundee	Dog C	4 September 2018	Active
Couple 4	Edinburgh	Dog A	9 April 2018	Placement ended
Couple 5	Glasgow	Dog A	17 May 2018	Active
Couple 6	Aberdeenshire	Dog D	20 August 2018	Active
Couple 7	Forth Valley	Dog E	12 December 2018	Active
Couple 8	Edinburgh	Dog F	7 January 2019	Active
Couple 9	Forth Valley	Dog G	25 February 2019	Placement ended
Couple 10	Forth Valley	Dog H	18 March 2019	Placement ended
Couple 11	Fife	Dog G	16 July 2019	Placement ended

Placements by location

Dogs placed (by location) within current Dementia Assistance Dog Programme.



Henry, Anne and Uno's story

'Uno is my reason to get up in the morning.
He is the best present I have ever had.'

Uno is a male Labrador x Golden Retriever and was born on 10th February 2015. Highly intuitive to people's emotions, Uno loves learning new tasks and being around people – he greets everyone with a big wag of his tail and is only too willing to offer to help around the house. Uno's intuitive nature means he really enjoys his task work, and coupled with his sensitive and friendly personality, this made him a perfect dementia dog. Having completed his basic training, Uno travelled to Scotland and was placed with Henry and Anne in May 2018.

Uno's ability to adapt to a diverse range of busy environments, along with his beautiful gentle nature with other dogs and small children was a key consideration in his match with Henry and Anne. Henry has been living with vascular dementia for more than ten years. He became depressed following his diagnosis of dementia and as Anne explains, '*Prior to getting Uno, Henry's dementia stopped him doing a lot of things.*'

When they first met Uno, Henry and Anne were excited, if a little apprehensive because they did not want to let Uno down. They need not have worried as they all 'took to it like ducks to water'. Uno has formed very close bonds with both Henry and Anne and is included in everything they do. This includes daily activities such as shopping and eating out, supporting Henry to undertake his role as a dementia activist, and regular trips to London to visit the couple's family.

Uno supports Henry with a number of practical tasks, including helping him to get out of bed by using a gentle nudge in the morning, fetching Henry's medication at

the sound of an alarm, and nudging Henry to remind him to eat when Anne is not at home. Henry travels a lot, both locally and further afield to visit family, and can find this stressful. Uno has been trained to rest his head on Henry's lap when he senses that he is agitated or distressed, which helps Henry to feel more at ease. Uno is a constant companion for Henry and, as a result, Henry is able to continue his activism, which is an important part of his life. In Henry's words, '*Uno is my reason to get up in the morning. He is the best present I have ever had.*'

Anne also benefits. Uno provides reassurance that Henry is safe at home and Anne finds herself more confident to leave the house, more relaxed when she is out and less inclined to 'clock watch'. Anne also feels fitter because of increased walking with Uno and feels the benefits of getting outdoors.

It is not just Henry's experience of dementia that has been impacted on through Uno's presence. Henry is also living with diabetes and his insulin levels have stabilised, during the period of Uno's placement with the family, which they believe is a direct result of Uno's assistance. By retrieving his medication at set times, Uno reminds Henry to take his insulin. On several occasions, Uno has detected that Henry's blood sugar was low and signalled this by persistently nudging Henry and not leaving his side. As a result, the dog team is investigating the options for having Uno dual-trained as both a dementia and medical assistance dog, a great example of the collaborative nature of this pioneering programme.



Uno resting his head on Henry's lap, which helps Henry feel more at ease.

Information collected (evaluation data)

Evaluation data for Couple 1, Couple 2 and Couple 3 were collected by the Dementia Assistance Dog Programme team. However, following a review of workload by the dog team, it was agreed that, for new couples, the evaluators would assume this task. This change was intended to support the dog team to focus on training, advice and support relating to the dog and its placement in a couple's home.

The questionnaires within this evaluation captured information about carer stress (referred to in the

tool as caregiver burden) and service use. Where a couple wanted to use pedometers, these measured physical activity. Journals, video recordings and follow-up interviews collected insights into the impact the assistance dog has on supporting people to live well with dementia, with a focus on the wellbeing and physical activity of both the carer and the person living with dementia from their own perspective.

Data gathered are summarised in Appendix Three.



Ann and family with Hope

Cost of assistance dogs

The average organisational costs for provision and lifetime support of a dementia assistance dog is £25,000. This can be broken down as follows:

- Training costs (including salaries of professional dog training staff) for the dog to undergo two years of specialised training – £13,500
- Charity costs to provide continued aftercare support for the lifetime of the dog – £11,500

With regard to this programme, the costs for eight (fully trained) assistance dogs is approximately £108,000, with a further £69,000 in ongoing support costs for the six active dogs. This is a total cost of £177,000.

Due to the constantly changing nature of dementia, the project team have structured ongoing support on a more regular basis than with other types of assistance dogs which typically receive a face-to-face check-in visit once a year.

For families participating in the dementia assistance dog programme, the dog team aims to visit every three months, to ensure that the dog's training and skills are adapting to any changing needs.

The dementia specialist role within the dog team has been a crucial source of broader, holistic support for families. This part-time role ensures dementia-specific, timely support is available for families, both to maximize the long-term benefits of their partnership with the dog and to foster a proactive approach around crisis prevention.

Findings

Throughout the 12-month evaluation period, participants were asked to record their family’s experiences, interactions, thoughts and feelings in a journal, at least once a week. Written journal records were made primarily by unpaid carers, with a small number of records written by people living with dementia. Handwritten journals were then typed using a transcription service and imported to NVivo 12 (data analysis programme).

Thematic analysis is a method for identifying, analysing, and reporting patterns, or themes, within data. Braun

and Clarke’s (2006) six-phase framework (Fig. 1) was used for thematic analysis of the narratives contained within the journals. Each segment of data that was relevant to, or captured something interesting about, the evaluation was coded. Not every piece of text was coded, and a list of pre-determined codes (Table 3) was used. Pre-determined codes were selected based on a review of the two former dementia assistance dog programme evaluations and were modified and added to throughout the coding process.

Figure 1. Braun and Clarke’s six-phase framework for thematic analysis.

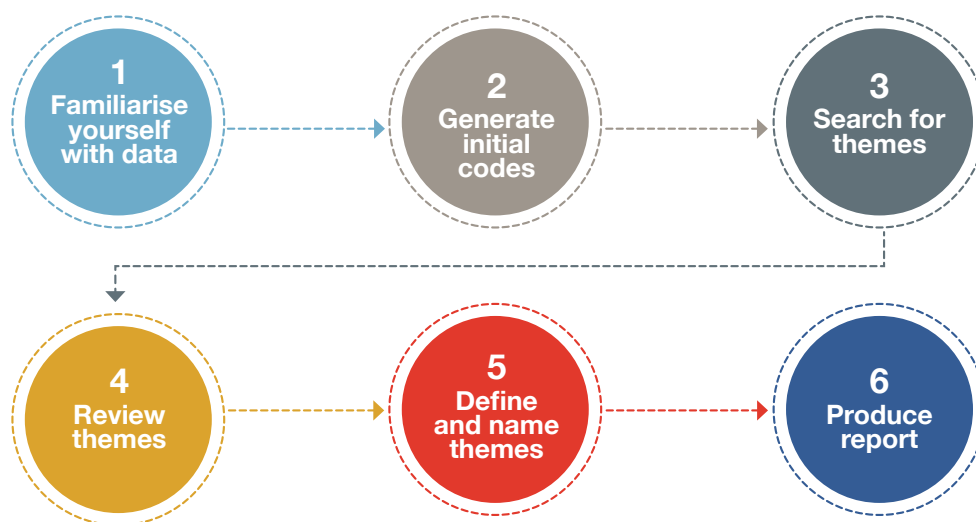


Table 3. Predetermined codes.

Carer stress	Health	Self esteem
Confidence	Independence	Social isolation
Coping	Physical activity	Wellbeing
Crises/emergencies		

When all the data had been coded, themes were searched for within the coded extracts. The generation of themes involved the use of the visualization and query tools within NVivo. Identified themes were then added to NVivo and the coded extracts incorporated into the relevant theme. At this stage, any themes which did not have enough supportive data were excluded and those which were considered to be sub-themes were incorporated into the overarching theme. Appendix Four provides an outline of the process.

Themes emerged around the carer experience, domestic co-productions (Christie, 2018), the dog as a point of continuity in peoples’ lives, the dog as a social bridge in building social capital, promoting feelings of ‘togetherness’, the dogs as public symbols in ensuring that dementia does not remain a hidden disability, and evidence of physical activity. Some of these themes intersect and are explored later in this report.

The following section details the themes, using journal extracts in italics to exemplify each theme, or elements of it. Names have been changed to preserve anonymity.

The carer experience

Carer wellbeing is a theme which includes getting space and time outdoors, companionship of the dog, taking the focus off the negative, and hope.



Ann and her granddaughter with Hope

The carer experience

The role of carer for a person living with dementia is a complex one, with constantly changing family relationships, domestic and social roles all playing a part. The impacts on carers of providing support for a relative with dementia are well documented. Carers of people with dementia, for example, are more likely to become depressed (Cuijpers, 2005) or have poorer physical health than their non-caregiving counterparts (Sörensen et al. 2006). Carers of people with dementia also experience social isolation and loneliness, with more than a quarter of carers feeling 'cut off from society' (Alzheimer's Society, 2017).

Throughout the journals, there were many references to carers' enjoyment and appreciation of their morning or afternoon walks, or 'free runs', with their dogs. For most carers, although an additional commitment in terms of time and energy, this has become a welcome routine that gives them assured time outdoors each day. For many carers, this provides an opportunity for self-care. A number of carers also reported visiting new parks, beaches or green spaces with their dog. This is important because we know that there is a positive impact of being outdoors, particularly in natural environments, on mental health. Duggan et al. (2008) found that carers of a person with dementia reported decreased frequency in their outdoor activity and a

scaling down of the places they would venture to, only visiting those areas that were most familiar. Both the Dementia Dog Project and Dogs 4 Dementia project evaluations reported an increase in physical activity levels among carers, however, this was not explicitly linked to mental wellbeing. Within this evaluation, maintaining outdoor activity through regular walks and runs with the assistance dog, including visiting new environments, appears to uphold wellbeing among carers.

I am finding I get stressed at times fitting everything in as well as walking her but find that the process of going for a free run with her calms and relaxes me.

Later our walk together blows the cobwebs away.

Just a tonic for me it was great to have the early morning walks again. Fresh air and exercise with her are a very good way to start the day. Even given the worry about Ben's health.

We enjoyed our usual morning walk together when Ben was still in bed. Her joy of being out in the open is catching and lifts me up to start the day in a more positive way than I otherwise would.



Jon and Jeannette with Lenny

The carer experience

Many carers feel emotionally supported by their dog due to the companionship it gives them. The dog is like a friend to talk to when things are difficult and helps them feel more able to cope with a bad day. This is consistent with findings of both the Dementia Dog Project and Dogs 4 Dementia project evaluations, which reported that the dogs provided emotional support for both the person with dementia and carer.

Early mornings are our private times, gives me a lovely morning greeting – even if I don't feel like facing the challenge of the coming day. She cheers me along with her antics and I get on with it.

There have been periods over the last few days that I have found emotionally difficult as Graham's behaviour changes with the progression of dementia, but having Ola to give a hug to helps me through this.

I've found it quite hard going recently with Ben's moods and behaviour, feeling a bit sorry for myself but when I get up in the morning – sometimes still rather early – it's so lovely to have her nearby. Our special time together.

But it's not just Graham. I often feel she does more for me than him. It's nice if I'm feeling fragile to be able to take her anywhere.

The day after was not a good day for either of us. Graham was tired and therefore not functioning well and getting angry, which I found very upsetting. I don't know how I would have got through the day without Ola's love and support. I kept her with me through the day, including delivering posters in the shops, which of course she is allowed to enter, and the attention she generates and the constant presence was so comforting. She really is very special and her having access to everywhere makes all the difference for both of us.

Ola has become a big part of my life and gives me a lot of the emotional support that Graham is increasingly unable to give. I give her a free run every day and she accompanies me if I go out with the local rambling club and as a consequence, I am much fitter. She has also meant that I get to know more people as again, she draws people to her because she is so friendly and a lovely-looking dog. Even my non-dog-loving friends admit to having a soft spot for Ola.

I really can't imagine life without her and our lives would be a lot darker.

How I do not feel quite so alone at the end of a difficult day (like today), when we can exchange a look across the room, Max looking quizzical (may only be that he wonders when the next treat is coming!). And in turn Charles benefits by Max giving me the strength to cope.

The time I have with King and myself are very precious to me and can make the most stressful days a lot better.

The carers' journals also reflect hope – the dog helps to take the focus off the negative, provides a lightness and humour, and makes the carer feel more optimistic about the future. This finding was not reported in the previous dementia assistance dog evaluations and may have important implications. Hope has been shown to help female carers of people living with dementia balance everyday stress and wellbeing (Irvin and Acton, 1997). This is supported by research into the experience of carers of palliative patients, whereby hope was identified as an important resource for managing the caring experience (Holtslander et al. 2005). Duggleby et al. (2009) report on the hope experience of 17 carers of people living with dementia. The authors conclude that fostering hope should be an important part of supporting family carers. In summary, hope may be a key psychosocial resource for carers and the findings of this evaluation indicate that dementia assistance dogs can help to foster hope among carers.

Instead of facing winter with not much to look forward to we have been wakened out of our lethargy and sense of sadness by this dear dog. The future feels so much more positive and bearable.

Presence is a very positive input in our every day lives. Takes the focus off the negative issues we are more and more confronted with.

This year has had its problems for Eddie and myself but with King help his gentleness and great nature we both have come out the winners. So roll on 2019 it certainly can only get better for us both with King by our side.

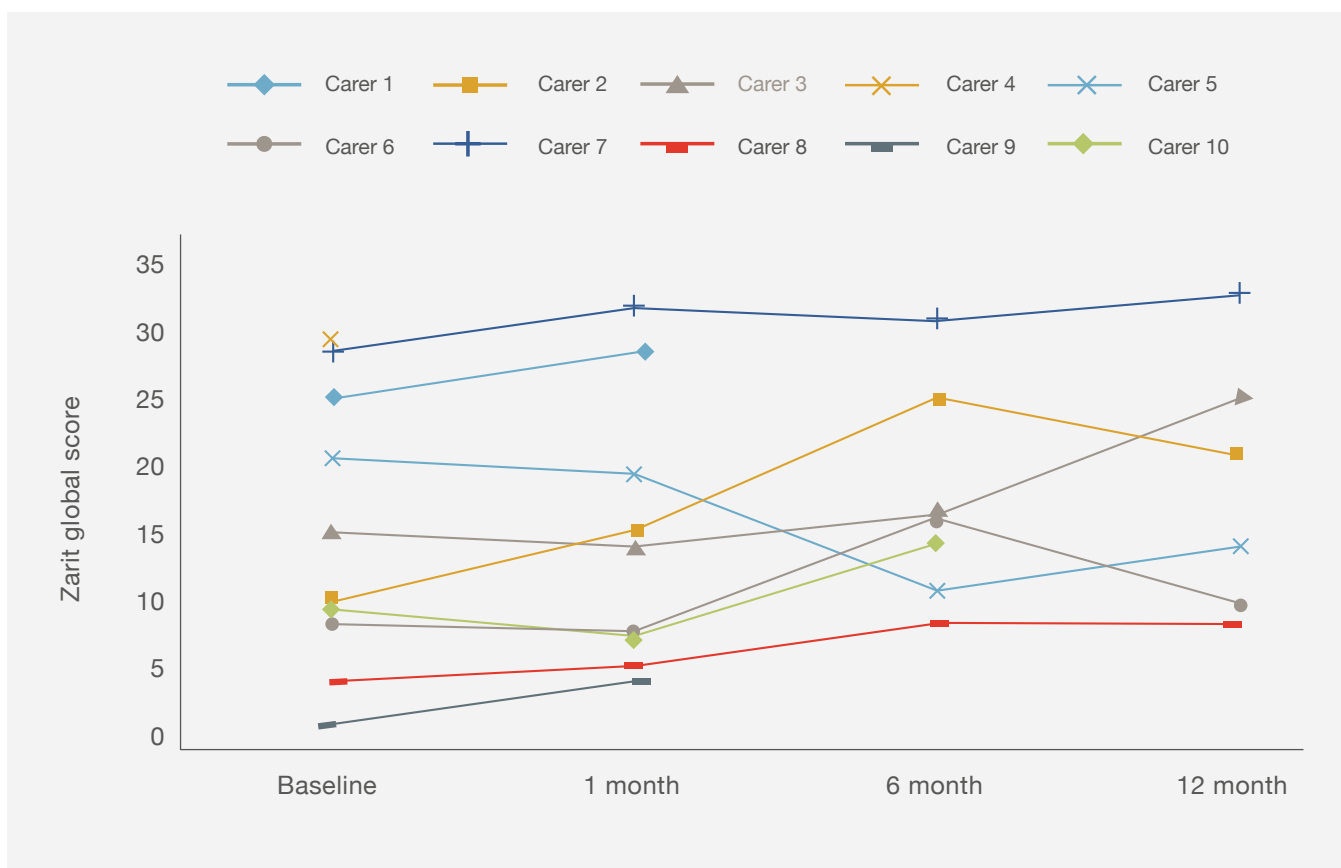
As long as Nero is also part of our lives he makes Alzheimer's that little less frightening. When you or your partner receive a diagnosis, it feels like your life is closing down, but Nero has opened up a new world. Fred has suffered from depression for most of his life but Nero provides a positive start to the day.

The carer experience

Another aspect of caring, so-called caregiver burden, was also considered within this evaluation. Perceived caregiving burden is commonly used to identify carers who may benefit from additional support or intervention. Caregiving burden¹ was assessed using the Short Form Zarit Burden Interview (ZBI-12) at baseline, 1 month, 6 months and 12 months following the dog's placement. Global ZBI-12 scores are summarised in Figure 2, where 0-10 represents no to mild burden; 10-20 represents mild to moderate burden and >20 represents high burden. See also Appendix Five.

The questionnaire data do not offer any definitive insights into a reduction of caregiving burden for individual carers directly linked to having an assistance dog.

Figure 2. Short Form Zarit Burden Interview scores over time.



¹Caregiving burden is defined as the extent to which caregivers perceive that caregiving has had an adverse effect on their emotional, social, financial, physical, and spiritual functioning (Zarit et al. 1986).

The carer experience

For most carers, level of burden scores fluctuated between baseline and 12-month follow-up, with a general increase in score between these two time points. One carer experienced a consistent decrease in score from baseline assessment to 12-month follow-up. Considering the scores within the context of the person's circumstances helps to make sense of the details.

Carer 2 had a score indicating high burden at the 6-month data collection point. This data collection point was delayed to 9 months because the family member with dementia was admitted to hospital on five separate occasions between 6 and 9 months following the dog's placement. These hospital admissions and the related stress that naturally accompanies hospitalisations is likely to have contributed to the rise in carer burden for Carer 2.

Carer 3 had a high carer burden score at 12 months following the dog's placement, with an increase of 8 points between the 6 and 12-month data collection points. This carer's spouse was in a specialist care centre for the 25 days prior to and during this data collection visit, which may account for the increase in score.

Three carers scored for high burden at the baseline assessment. Two of the three placements involving these carers did not continue beyond three months. The high score at baseline may have been an indicator that the carer was in need of support, and that the addition of a dog into the household would not have been timely at this point. One of these carers was not accessing any other support at the time of the dog's

placement. More data would be needed to draw firm recommendations, however, the Zarit Burden Interview may provide a brief screening tool for the dog team as part of their initial assessments.

Examination of participants' use of services (P32) does not offer any additional insights, i.e. on the whole, higher carer burden does not appear to correlate with lower use of services, or vice versa.

The questionnaire used in this evaluation focused on the negative aspects of caregiving and the associated burden. However, recent research suggests that, even when experiencing high caregiver burden, many carers also experience high benefit from their caring role (Pristavec, 2019). The research builds on the theory that negative and positive perceptions of caring co-exist. As an example, a carer of someone living with dementia may experience feelings of accomplishment, or develop new skills and knowledge, whilst also experiencing interpersonal burden. Future work in this area may profit from considering this ambivalence around caring, and if and how perceptions of benefit among carers of people living with dementia can be influenced. The example of the assistance dog could be a foundation for such a discussion.

In summary, it is useful to know about carer stress and perceived burden and the ways in which the assistance dog can contribute to wellbeing and hope during times of stress. There is clear evidence that the dog has a significant impact on carer wellbeing despite the experience of caregiver burden recorded.



Imke with Webb

Domestic co-production

This theme reflects a new triadic relationship in the households, whereby all of the family members know and understand what their dog can do for them. The dog performs its role as an active member of this co-production; the other members can use the dog confidently as a resource, rely on the dog, and the dog has very much become part of their caring 'team' that is adjusting to life with dementia. This represents a shift from a dyadic relationship involving only the person living with dementia and their spouse/unpaid carer. This can greatly relieve the sense of isolation that caring for a person with dementia can bring. But it also promotes the dignity of the person with dementia as a member of the domestic co-production. This is a subtle but often missed aspect of being a recipient of care.

The relationship within the household is, therefore, one of interdependence. Many carers reflected in their journals the dog becoming an integral part of the family – one of the 'three of us'. People living with dementia have indicated that they value interdependence over dependence or independence, i.e. 'they neither valued the care-partner taking over full responsibility for everything nor the person with a diagnosis of dementia having total independence' (Keyes et al. 2018 p308). Dementia assistance dogs are uniquely trained to take commands from both the person living with dementia and the unpaid carer. This triadic partnership may help to facilitate interdependence within the household, through shared responsibilities, a new sense of connection and common ground.

The amazing thing is that Eddie has such an attachment to King that on a bad day he is the only thing he will get out of bed for, and even makes him smile and he will interact with King and no one else not even me.

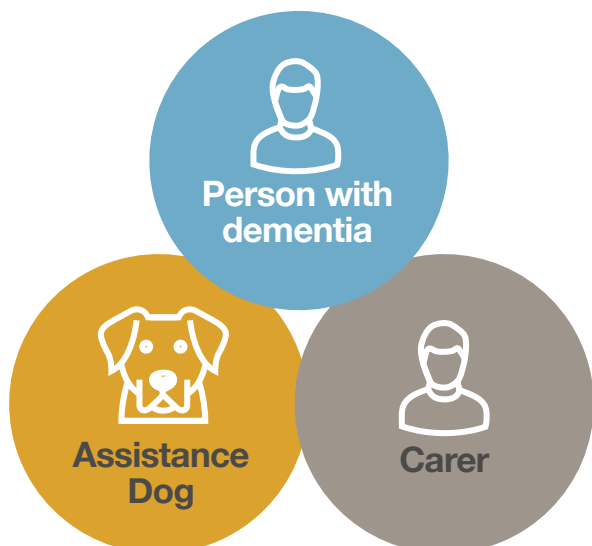
On Friday when I got home I got such a welcome home from King it was lovely. It was so nice to get back to the three of us. We have become such a good team.

Nero owns me as much as me (us) owning him.

This is a quiet week for us Eddie has only one meeting it is actually nice to spent time just the three of us. We have gone out for lunch and coffee and Eddie and I took King to the park.

If we're having a bad day, Ola is our absolute rock. She's just a loving, sappy dog who always wants a big hug.

Figure 3. Triadic, interdependent relationship between family members and assistance dog.



Domestic co-production

An important element of this new model of domestic co-production is the relief of tension or pressure within the household and the avoidance of flashpoints, both through the provision of task-based support and through the innate sensitivity of the dog, as captured below. This is a new finding in terms of the role of dementia assistance dogs in supporting both the person living with dementia and the unpaid carer, and appears to contribute positively to the dynamics within the household.

If I tell Charles off for (yet again) having spilt the coffee or mislaid his glasses, Max quietly joins us and steps between us, as if to say 'can I help?'

In the morning I let her out and she comes inside rushing upstairs and wakes Graham up without a murmur from him. If I told him to get up at 7am it wouldn't work but there's not a word to Ola.

The use of the dog to provide task-based support varies among the families. For some families, task-based support is something that is practised for when it is needed, rather than for the here and now. For others, the use of tasks provides very practical support and reminders, most commonly gentle wakening in the morning, retrieval of medication at different points throughout the day, and reminding the person to eat or drink at a specific time. These findings are consistent with the first phase of the Dementia Dog Project which found that the person with dementia was supported with new tasks as time went on and they needed additional support.

When he wakened he chatted to Luna and gave her a dog biscuit when she brought his lunchtime tablet. We've trained her to take the container back to the kitchen, which she does proudly.

We've got back to more of a daily routine at home, she brings our slippers and his Medi.

This morning she wakened Ben, gave him his morning licks then just lay beside him and I saw him stroking her. When we got back from our morning walk Ben was having his shower, much to my surprise as he hasn't done that alone since becoming ill nearly 6 weeks ago.

Fetching medication at 1 pm and 6 pm, particularly important, as it has to be taken at regular times.

King was taught to nudge Eddie and this will be used to remind Eddie if I am not with him to eat his lunch or dinner when a timer goes off.

King is also trained to wake me up in the morning. King taps his nose off the back of my hand. If I don't wake up on the third attempt, King goes downstairs and alerts my wife.

Task-based support can also be subtle, yet profound. An example of this is one family member using the command for the dog to open the door by pulling a grab handle. In fact, this person was experiencing challenges finding their way out of the room. In asking the dog to open the door, a common command for an assistance dog, the person was able to find their way out of the room, without the need to disclose that they were having these difficulties with wayfinding. Sørensen et al. (2008) report that people living with mild Alzheimer's disease have an awareness of decline in personal dignity and value where 'actions, that previously were easy and natural, became difficult or impossible to perform. Use of the dog in this way may help to preserve a person's dignity through active adaptation of everyday activities.

Finding and opening doors downstairs in the living room, Charles sometimes becomes disorientated and cannot find the way out any more.

Dog as a point of continuity

This theme relates to all family members, however, may be more pertinent for the person living with dementia. The dog is a constant – always there, whether at home, travelling or at places new or familiar. Full access rights allow the dog to go everywhere and be that constant support – something that is not possible with a pet dog.

I often get anxious in large queues. King travels with me and just lies on the floor. I keep his jacket on so people know he is a working dog. King helps keep my independence.

It's nice if I'm feeling fragile to be able to take her anywhere.

The dog's presence is helpful in new, unfamiliar or disabling environments, or situations that a person might find stressful or feel anxious about.

Ola did a good job of calming down Graham this morning. He was taking the train for a meeting and was very anxious about meeting up with the others and generally getting things right. Doing dual lead to the train kept his mind off the journey and more on Ola which made things a lot easier.

He feels supported when Ola goes with him and he loves the attention she gets - he loves to show her off! He would be very reluctant to attend these events without her. In fact, he often initially doesn't want to go somewhere until I say he can take Ola, to which he replies, 'Okay, I'll go'.

The dog is highly sensitive to the person's needs and emotions and adapts its behaviour accordingly, providing reassurance and comfort.

The most important thing that King does is if Eddie is agitated or distressed in any way King has picked this up on several occasions he just rests his head on his lap and Eddie relaxes.

Luna is amazing, after months of being off the lead a lot and only with her coat on near roads and going into shops, when Ben was with us she immediately went back to a calm, sedate working dog.

Today we visited a place which had a lot of sheep, narrow winding steps and uneven ground. I led Ola as it allowed Graham to concentrate on getting his way around safely but I noticed she acted as a forewarning to other visitors that there was someone needing a bit of extra space and time.



Peter and Veryan practising head resting with Ruby

Dog as a social bridge

This theme reflects the role of the dog in supporting families to stay connected within their communities, supporting people to maintain existing networks and to form new connections. Throughout the journals, there was much discussion about the dog being a conversation starter and a 'connector of people'. The dog is both a motivation and a reassurance for the person with dementia in getting 'out and about' in their local community.

People living with dementia are at increased risk of social isolation when compared with other social groups, with more than a third of people with dementia reporting feelings of loneliness (Alzheimer's Society, 2017). Carers of people living with dementia also experience social isolation and loneliness.

Ben is now not just someone to be tolerated for a short chat or at worst ignored. Luna is his future to have more conversations and contact with people.

Reading this over I forgot to also mention a very important thing that Luna is our contact to the outside world, be it morning walks alone with her meeting other dog walkers, or with Ben for short walks or at meetings for people with dementia and their carers, where Luna is a firm favourite.

For Graham, she has brought support, comfort, a sense of fun and the incentive to go out and take part in activities. If he can take Ola with him, he's usually willing to go as he loves to show her off and she attracts admirers wherever she goes. And thus, conversations are started with all sorts of people who we would never otherwise have met.

Luna continues to be a great companion for us both. She comes with us to our local group and is a firm favourite with the people there and Ben enjoys the attention he gets because of this.

Encouraging interactions with other people, rarely do I go out for a walk without talking to somebody about Max's role and its impact, and repeat meetings with relative strangers are very comforting, when they remember Max and ask after Charles.

We are continuing to go out with King every day either to go for a coffee, shopping or to the park. Not a day goes by now that we are not out and about and I no longer need to make Eddie go he is now more than happy to go out and sometimes he even suggests it.

We had a outpatient appointment at the hospital, gone out for coffee, lunch, and the cinema. King is so used to going to these places and we all are very comfortable where ever we take King. In fact, King definitely makes more people talk to Eric and in turn Eric can be more talkative in the house.

Furthermore, being involved with the Dementia Assistance Dog Programme has navigated a number of the families to additional support, e.g. via local dementia networks and carer groups.

Being part of the Dementia Dog Project is like being a member of an exclusive club. A bit like having a black credit card. After struggling to find much support doors are now opening because we are involved with amazing people who give so much of their time and expertise.



Peter and Veryan with Ruby



Jon and Jeannette with Lenny

Togetherness

Throughout the journals, there were many references to a physical closeness between the person living with dementia and the dog, including lots of stroking or ‘clapping’, nuzzling and close contact.

Throughout the journals, there were many references to a physical closeness between the person living with dementia and the dog, including lots of stroking or ‘clapping’, nuzzling and close contact. This gives the person comfort, reassurance and relaxation. In each case, the person with dementia enjoys spending time in the dog’s company. There is no expectation, e.g. of conversation, and no judgement. The dog is highly sensitive to the person’s emotions and knows when they are needed most.

In examining the relationship in the context of loss, e.g. following the death or retirement of an assistance dog, Kwong and Bartholomew (2011) describes the relationship between assistance dogs and the person they support as one of attachment. Research participants (people who were legally blind or physically disabled) identified key components of attachment in their relationships with their assistance dog, namely i) a safe haven – people turned to their dog for comfort when they were distressed, and ii) a secure base – people perceived their dog as a dependable source of comfort and support, enabling them to cope with stressful experiences. This is supported by other research that evidences attachment between children and companion animals (Melson, 2003) and people living with dementia and either service dogs or animal-assisted therapy dogs (Dyer, 2019).

Kwong and Bartholomew (2011) also identified the importance of the caregiving element of the relationship. Within the Dementia Assistance Dog Programme, both the person with dementia and the carer provide care for the dog, including feeding, grooming, toileting and exercising. This shared responsibility may help facilitate an attachment relationship across the triad.

Kwong and Bartholomew also highlight ‘contact comfort’ as important in the attachment relationship of assistance dogs and their family member. This is consistent with the findings from this evaluation which suggest the dogs meet the person’s need for physical comfort and closeness, particularly when they are

feeling anxious or low. Furthermore, the combined training and innate sensitivity of the dementia assistance dogs means that the person living with dementia does not need to communicate this need for contact comfort and, instead, the dog comes to them.

Max resting his head on Charles’s knee, just quickly checking in, that all is well.

I’m writing this for Fred who seems to have become incapable of writing his own journal. He said to me today that Nero has made life more ‘tactile’. I know exactly what he means - Nero’s presence is very physical and he’s constantly wanting to nuzzle up to us and we’re constantly stroking him, scratching him or grooming him! I think this is very relaxing for me and therapeutic for Fred. When what’s going on inside your head is difficult making contact without words and on a physical level is grounding in a positive way!

I thought I had flu last night – sweating, aching legs, etc., etc. I lay down on the sofa and after a few minutes along comes Nero licking me all over, trying to shake hands, resting his head on my stomach and staying there a long while. He stayed close the rest of the evening looking sad and subdued until I got up and went to bed and he came back to life. Probably trivial but very moving for me.

I was out most of the afternoon so Ola and Graham kept each other company. He took her out in the garden and threw the ball for her and they listened to music together with Ola lying at his feet. They were both quite happy when I got home.

Fred can’t bear to be without Nero now. He’s the one thing always guaranteed to make him smile.

Ben felt light-headed when we got home and lay on the bed. Luna lay next to him until tea was ready.

Physical activity

Ben said he feels he hasn't walked as much since he was in the army.

Each couple was asked to record their physical activity by way of number of steps using a pedometer provided by the dog team. Some people already used a fitness tracker to monitor health and physical activity and so chose to record their steps using this instead. It was agreed between the dog team and the couples that they should record a five or seven-day 'snapshot' of their physical activity levels in the week prior to each evaluation point.

A number of carers and people living with dementia had problems wearing the pedometer and data for this component of the evaluation is either incomplete or absent. Only one couple recorded a full dataset for both members of the household and one carer recorded a partial dataset for both members. These data are summarised in Figures 4 and 5 respectively on page 35.

For both carers who recorded their number of steps, there is an upward trend in the average number of daily steps, indicating that the level of physical activity increased for both these carers between baseline and their final recording (12 months following placement for Carer 5, 5 months following placement for Carer 7). Both carers experienced a decrease in their average number of steps at one time-point, however, the general trend was an overall increase. For Carer 5, the decrease in number of steps was related to being away from home and for Carer 7, the decrease coincided with bad weather.

Person with dementia 5 demonstrates the opposite trend, with the average number of daily steps showing a general decrease between baseline and 12 months following placement. Data for this participant should be interpreted cautiously since they had sustained an injury prior to the dog's placement and were continuing to have treatment throughout much of the evaluation period.

Person with dementia 7, on the other hand, shows a modest increase in the average number of daily steps between baseline and 3 months, following which the pedometer was lost and no further recordings made. Journal records for this participant, however, indicate that the increased level of physical activity was maintained throughout the programme.

This quantitative data on the number of steps, although indicating an increase in physical activity for two carers and one person living with dementia, should be interpreted cautiously. Data for this element of the evaluation is limited and physical activity may be best analysed through the journal records kept by carers. The journals indicate a general increase in the amount of walking since the dogs' placements, particularly for carers but also for some people living with dementia.

The journal records also reflect walking becoming an everyday routine with the dog, with carers indicating a high level of enjoyment on these walks for both themselves and their spouses. Many journal entries refer to long walks with the dogs and walks are almost always discussed in a highly positive way. A number of carers also noted that having the dog motivates them to go out on days when they would otherwise not, e.g. during bad weather or when they are feeling low.

Nero, however, continues to be a huge source of comfort and pleasure. He makes Fred want to go for a walk which he never did before, relieves tension and generates happiness, not just for us, but for friends and other visitors.

Unrolling the yoga mat. Ok, I could do this, but would sometimes just receive an annoyed grunt and a "cannot be bothered" comment. If however, Max stands there, tail wagging, all pleased with himself, and then joining Charles on the mat, who can resist!

I felt very low this morning, feeling overwhelmed by the reality of now living in the world of dementia. Going for a walk has always raised my mood, but I know I would never have gone this morning had I not had Ola to walk. I certainly felt better and it was pleasant to exchange a few words with other dog walkers.

Physical activity

Figure 4. Physical activity data for Couple 5.

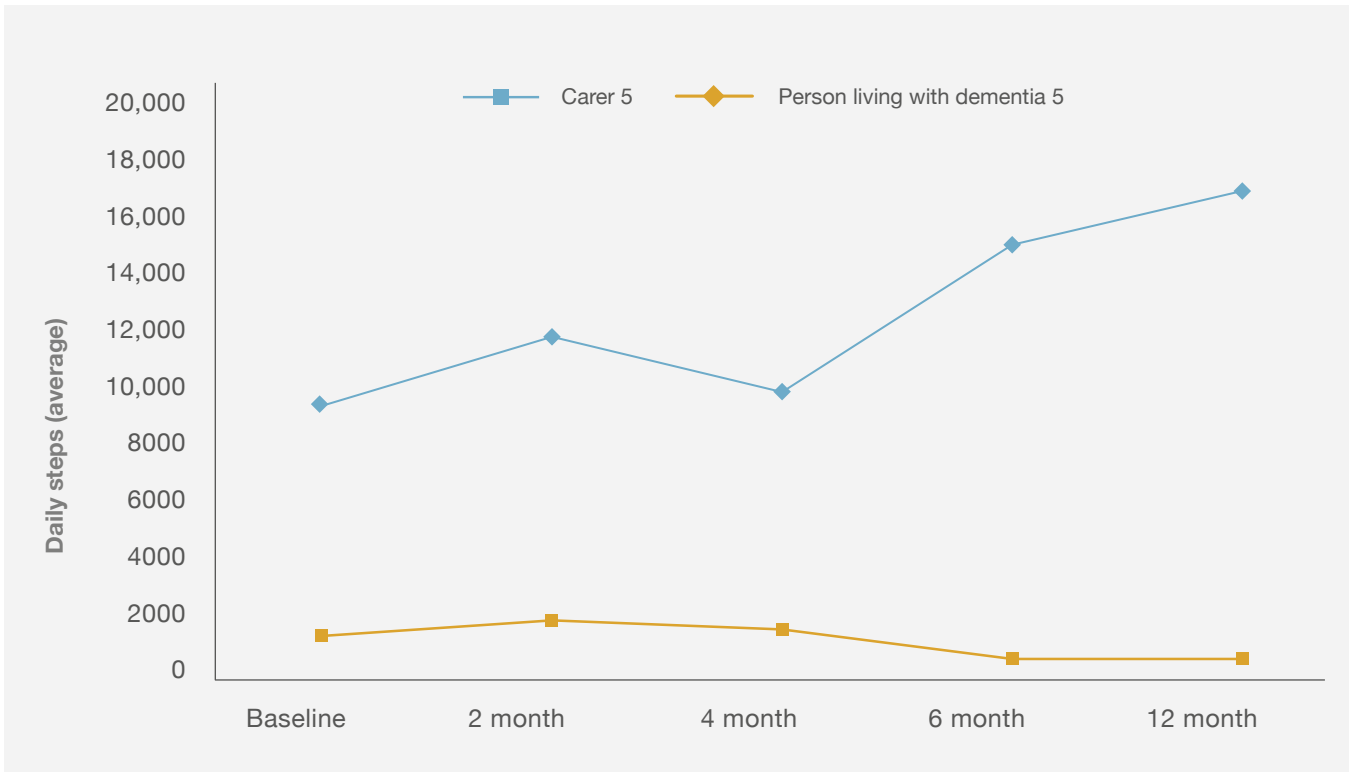
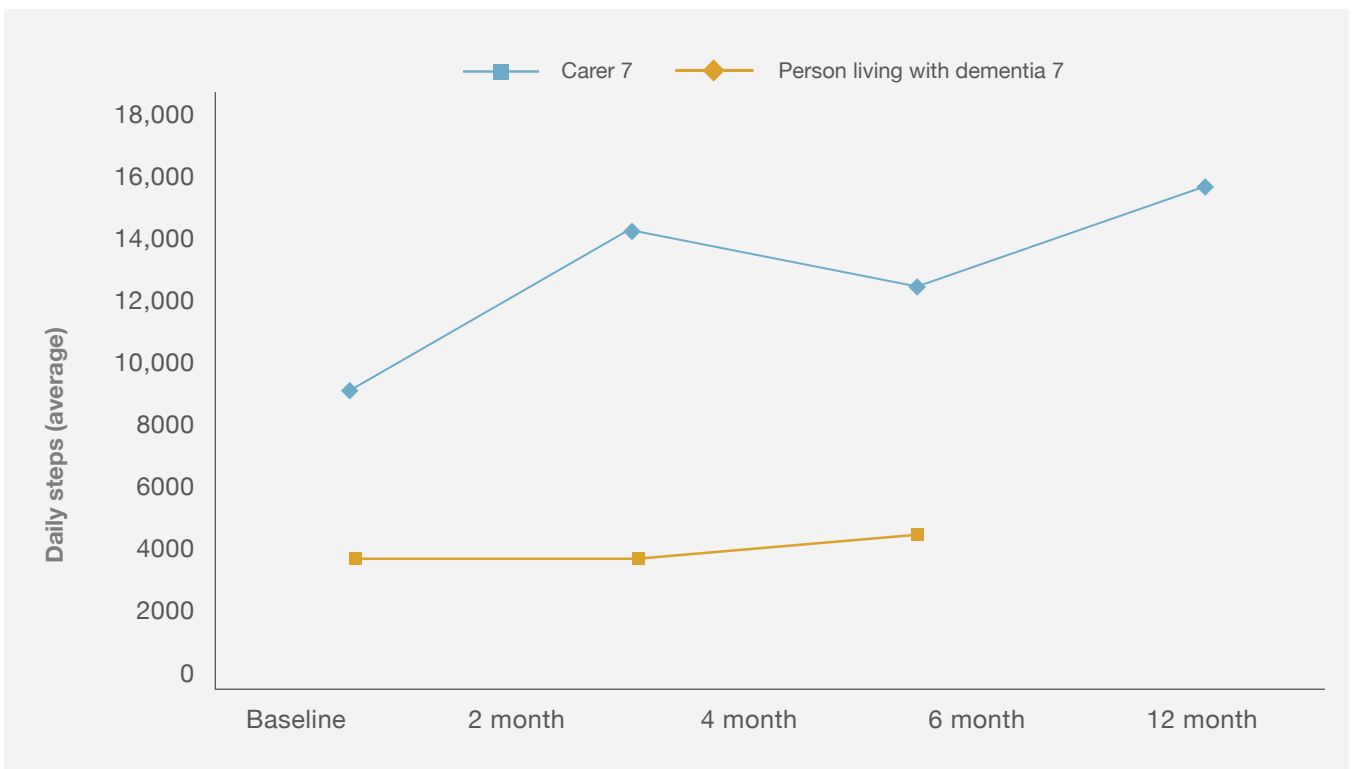


Figure 5. Physical activity data for Couple 7.



Dogs as public symbols

This theme reflects the dogs facilitating greater awareness and education about dementia within the communities in which they live. We have previously described the role of the dog in supporting people to remain/become socially active within their community. In doing so, the dog attracts a considerable amount of positive attention, providing an opportunity for families to share the reasons they have the dog and how it supports them, as well as talking about dementia more generally. This is consistent with research on autism service dogs (Burrows et al. 2008) which found that, by facilitating social interaction, the service dog improved people's awareness and understanding of autism.

As part of my fundraising, Ola and I were asked to go to the local golf club to have our photo taken with the ladies' captain's team. They had decided they wanted money raised from their annual event to go to the project. On arrival, I was told they had raised £200, which was generous for a small team. However, Ola was angelic, they all fell in love with her and subsequently raised another £200 after we left!

Ola and I took part in a Memory Walk yesterday. I raised £1,304 - far more than I expected - but it was really all down to Ola. Everyone who meets her thinks she is wonderful and wants to know all about the dementia dog project. In particular, they want to know what she does for Graham. They all think it is a wonderful idea because they can see what a difference Ola makes to our lives.

She is also a very popular and well-known member of the local community and has played her part in driving forward the success of the local Dementia Friendly Community.



Jan and Kurt with Willow

A snapshot of future care planning

None of the couples were in receipt of a formal care package during the evaluation period. This was also the case at the end of the evaluation period.

A common trend across the couples was the increased use of community-based, voluntary sector support, such as singing groups, lunch clubs, dementia specific information groups, and church-based services.

Much of this uptake in community engagement has resulted from the bespoke support provided through the project team's Dementia Specialist. The focus of this critical role has been four-fold; to provide specialist dementia guidance to the project team in assessing suitable applicants; referring applicants that don't meet criteria to our other dementia dog support programmes in the community; promoting the work we are piloting across health and social care networks and providing support to recipients of a dementia assistance dog as part of the team's ongoing aftercare after a dog is placed. Additionally, the Specialist has provided bespoke dementia training days for all project stakeholders including prison staff and students at HMP Castle Huntly involved in the dog's training. As an integrated part of the Dementia Dog Project team, this role ensures the programme holistically blends specialist dementia and dog knowledge to provide timely and appropriate support to families.

This role ensures that families with a dog are able to access appropriate dementia support, such as linking families up with the Digital team within Alzheimer Scotland to learn about and trial technology devices in the home that can work alongside their trained dog to futureproof their house, promote independence and further enhance a sense of reassurance, for both the person with a diagnosis and their carer. The role has also worked closely with families to identify unmet needs as they arise due to the progressive nature of dementia. This, together with the tailored training of each dog, helps retain a focus on prevention of crisis and carer stress - signposting families to appropriate agencies in a timely manner to ensure they are living safe and well in their own homes for as long as possible.

The Dementia Specialist also offers practical assistance and advice to ensure that the families are maximising eligible benefit and welfare checks, as well as helping to promote personalised support, their rights and entitlements when requiring social care support. A key area has been helping families navigate the health and social care system to access and secure Self Directed Support (SDS), which has proven a challenging process dependent on the local authority area. Currently, the Dementia Specialist has supported four of the client families (with a fifth in progress) in accessing SDS budget to help ensure they can live well and stay connected whilst living with a diagnosis of dementia.



Ann and John with Hope

Overarching themes

This evaluation set out to explore the impact of assistance dogs in the lives of people with dementia and their unpaid carers, including an analysis of economic impact. In addition to confirming the expected benefits (page 11), the evaluation team identified positive impact in the following areas:



The carer experience



Domestic co-production



Dog as a point of continuity



Dog as a social bridge



Togetherness



Dog as a public symbol



Physical activity

Overarching themes

Dementia assistance dogs provide something unique that is not currently available in traditional services and traditional service responses. Previous evaluations have highlighted the role of the assistance dogs in promoting independence, acting as a catalyst for social interaction, and being an anchor for the person with dementia. For carers, the dogs have been found to promote wellbeing and improve physical activity. This evaluation identified evidence of the expected benefits, and developed these further to reflect current dementia theory in order to paint a more detailed picture of the processes at play.

A key question throughout the evaluation was 'Would a well-trained pet dog offer the same benefits as an assistance dog for people living with dementia and carers?'. We found that the task-based support, while important for many participants, was secondary to the value of the relationships, warmth and pride that comes with having a dementia assistance dog. That said, the new domestic co-productions, created by the dog's presence, would appear only to be made possible because of the dog's unique training and right of access. For example, morning prompts prevent flashpoints if the carer is perceived to be 'annoying' the person with dementia out of bed. The dog, instead, is warmly welcomed and the person then rises in good humour. The dog opens the living room door on command, locating the way out of a room for a husband who otherwise would be noticeably lost and possibly diminished in the eyes of his family. The dog's task avoids this.

Resilience and social capital

Looking across the individual findings for collective themes, there is strong evidence that the dogs contribute to the resilience of the person with dementia and unpaid carers, separately, and together. Resilience is the process of adaptation in the face of adversity. People who are resilient can recover from stresses and challenges more readily. They do this by using assets and resources that can be employed in times of crisis. The mobilisation of assets helps us to reduce the impact of negative events and promotes recovery from shocks. Resilience is personal but our communities play an important role. Resilient communities have a high degree of social capital. Social capital refers to relationships, connections and networks (Putman, 2000). There are two types of social capital: bonding and bridging. Bonding social capital is the social networks that are built around our similarities and reciprocity, and includes close familial relationships, neighbourhoods or communities of

interest. Bridging social capital describes support which creates a sense of community cohesion, making it easier to access information, resources and support outside of the person's usual network, community or communities. Assistance dogs can be considered as an asset that can be called upon, but also a means of building personal resilience and a means of building social capital. This is explored in more detail below.

The key areas of promoting resilience in the context of dementia are defined by Christie (2020) as:

- A sense of connection with people and places;
- A sense of mastery and control;
- Meaning making opportunities.

A sense of connection

The more socially isolated a person is, the less resilient they may be to the changes taking place which can negatively impact on recovery. Unpaid carers can also experience stress and distress. Carer burden can increase as competing priorities arise. Feelings of negativity and hopelessness can also be present as the person with dementia loses the ability to initiate activities of daily living (Giebel et al. 2017). Individuals, both people living with dementia and unpaid carers, who have less social capital (friends, neighbours, formal supports, people to turn to) are more likely to be more impacted by crisis than people who feel connected to other sources of support. It is clear that the assistance dogs form bonds with the people in the home and connect the household to their wider community. Not to mention becoming part of the dementia dog world with all of the social bridging support that this team bring to people's lives.

A sense of mastery and control

The dogs foster a sense of self-efficacy and, in turn, self-esteem through their presence. The carer and the person with dementia care for the dog, and the independence that both can achieve through relying on the dog, as an anchor and as a point of continuity, is pivotal. The dog gives everyone confidence to venture out into more social settings and is a safety net for the unexpected. Again, the role of the dog team is essential, as the carer knows that he or she can refer back to them. The very act of being taught how to 'handle' the dog is an exercise in regaining some level of control over life with dementia.

Overarching themes

Meaning making

The moments of togetherness with the dog, speaking to the dog and talking to others about life with the dog all help to create moments of meaning making and reflection. The dog encourages conversation as people engage with the person with dementia, and they are, in turn, invited to tell the story of self and how the dog came to be part of their life. The peer support offered by the other dog placements helps to collectively make sense of 'our story' with dementia.

Citizenship, at home and within communities

Citizenship is an active process where a person with dementia achieves recognition and status through their everyday relationships with other people, communities and society. New ways of understanding dementia are needed as a person's dementia progresses and the nature of interactions change. We need to find ways of restoring relationships on the terms of the person with dementia and on the promotion of opportunities for the agentic self to emerge.

The findings demonstrate that assistance dogs support both the person living with dementia and carers in a multitude of visible (e.g. task-based support and assisted walking) and unseen (e.g. fostering hope and providing reassurance and comfort) ways in order to achieve this. Many of the benefits identified rely on the assistance dog's right of access. For example, the important role of the dog as a social bridge relies on the dog being able to accompany the person on public transport, into public buildings, cafés, shops, and anywhere else the person chooses to go. These day-to-day activities are the cornerstone of citizenship and the dog is a key resource in supporting the person's participation in social and civic life. The dogs act as a social bridge, not only in terms of connecting people and building relationships based on similarities and mutual experience, but also in facilitating access to the person's wider community and the resources and information therein. In doing so, the dog helps the person to build both bonding and bridging social capital.

Lessons from placements that did not continue

During the three-year project, the dog team completed eleven placement attempts that resulted in six sustained dog placements with families. This section explores the reasons identified for placements not working, and how this learning was adapted into the ongoing pilot.

The first placement encountered difficulties following some unexpected health issues of the carer. This highlighted the pivotal role of the carer in the long-term success of a dementia dog placement. As a result, the dog team introduced a new requirement that both the person with dementia and the carer needed to complete separate medical forms, signed off by their doctor, to confirm no known health conditions that may deem them unsuitable applicants.

The second unsuccessful placement was due to the dog and client with dementia not bonding during the week following arrival of the dog in their home. Although infrequent, it is acknowledged that this issue is occasionally encountered when placing assistance dogs. For this reason, the initial placement of the dog lasts for a three-month trial period before an access test is performed to formally qualify the family with the dog. No changes were subsequently made to the project processes, as all other factors indicated a good match between the applicants and the dog.

The third unsuccessful placement was due to a prognosis of ill health of the carer; the dog was returned to the team and no formal changes made to the project processes, due to the prognosis having been unforeseeable by the person's doctor. The team continued to provide support (through visits) to help the family through this difficult transition period.

The fourth unsuccessful placement was due to health deterioration in the person with dementia during placement, which increased stress levels for the carer culminating in the dog showing stress behaviour. Following attempts to continue a tailored placement training programme at a less intensive level, the joint decision was made between applicant family and the team that, in light of changing health needs of the person with dementia, a dog may not be the most suitable form of support for them at that point in time.

While these unsuccessful placements were demoralising for all involved, they also provided valuable learning as a part of this pilot programme. The examples above highlight the crucial importance of the carer's health in considering a suitable match with a dementia assistance dog. Equally, some of the reasons identified could not have been predicted and reflect the complex nature of dementia and the challenges that arise alongside changes. However, in context of the wider pilot, this is balanced against the evidence of positive outcomes resulting from successful placements, and the far-reaching benefits this brings for families in their community.

Overarching themes

Economic impact

The economic analysis within this evaluation focused on change in health and care support plans and use of medications. The dogs did not appear to have an impact on the support plans or medication use of the participants on the programme. The support plans varied in their make-up and complexity, reflecting the individuality of the people and situations, and possibly reflecting the fact that the dogs were placed across several different postcodes in Scotland. Indeed, some support plans were augmented as a direct result of the involvement of the dog team, who facilitated increased support on behalf of the person and their unpaid carer. However, what is not reflected is the role of the dog within the home, 24/7, 365 days a year. If such a service was to be funded by way of a human companion, this would significantly increase the costs incurred. Similarly, the constant, responsive nature of the support, built around a loving relationship cannot be replicated. The dogs essentially become part of the caring relationship, spreading both a sense of joy while, at the same time, providing practical support. As one participant noted,

the house at once became fuller and full of fun, when it had felt quieter and more hopeless before. There is no uptake in self-directed support in the care plans of the people in the study during the period of the evaluation. It is not possible to say if the dogs had an impact on the type of services that were employed.

The impacts that were most valued by the families on this programme are difficult to measure in financial terms – things like continuity, hope and a sense of togetherness and companionship. Further work may benefit from applying a social value lens to the cost benefit analysis of dementia assistance dogs, to ensure that what matters most to the people who benefit is reflected.

Moving forward

The evaluation team has conducted a brief SCOT analysis to assess and summarise the strengths, challenges, opportunities and threats for the Dementia Assistance Dog Programme moving forward. This is presented in Figure 6.

Figure 6. SCOT analysis identifying the Strengths, Challenges, Opportunities and Threats for the Dementia Assistance Dog Programme in Scotland.



In conclusion






This evaluation adds to the existing knowledge around assistance dogs for people living with dementia in a number of areas. The dogs contribute to a new model of domestic coproduction – a triadic relationship that facilitates interdependence through shared responsibilities, whilst diffusing tension and avoiding common flashpoints. The dogs foster or renew hope among unpaid carers and may be a key resource in managing the care experience. The evaluation identified improved carer wellbeing related to the dog, even in the presence of increasing caregiving burden. Although quantitative data is limited, carer journal narratives reflect an increase in physical activity and use of outdoor spaces related to caring for the dog. This was also true for most of the family members who were living with dementia. Whilst it may be argued that a well-trained pet could help the carer achieve these same benefits, assistance dogs differ in their consistently high levels of obedience training and the legal public access rights this affords them, to allow them to support their owners wherever they are. Coupled with a gentle and loving temperament, within this evaluation, there is evidence of attachment relationships between these highly intuitive dogs and their families.

In summary, this evaluation concludes that there is evidence of the significant impact of assistance dogs in the lives of people living with dementia and unpaid carers. Carers of people living with dementia experience stress as a result of the unpredicted and unwilling consequences of dementia and the changing roles and relationships experienced. Assistance dogs provide a constant resource, for both the person with dementia and the carer, and in doing so promote continuity in people's lives as they adjust to the changes of dementia, of needs and of support. The dogs represent a high cost resource, however given the highly-tailored nature of support, and the unparalleled outcomes for both the person with dementia and their unpaid carer in promoting resilience and citizenship, this service is currently unmatched by other traditional service options in Scotland.

The Dementia Assistance Dog Programme set out to explore if and how assistance dogs can improve quality of life for people with dementia and their carers. It is clear that this approach, together with the associated specialist team support, can provide a myriad of long-term benefits. Equipped with this learning, moving forward, it is hoped that the provision of dementia assistance dogs can continue to be part of a wider service to connect people with the joy of dogs in different community settings, to provide holistic and meaningful support that is tailored around the individual needs of people living with dementia and their carers.

Anyone wishing to contact the Dementia Assistance Dog Programme can do so using the contact details below.

Dementia Dog Project – Dementia Assistance Dog Programme

-  bark@dementiadog.org
-  info@dogsgood.org
-  dementiadog.org/
-  [@dementiadog](https://twitter.com/dementiadog)
-  [@dementiadogproject](https://www.facebook.com/dementiadogproject)

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Appendix One

About the Dementia Centre

About the Dementia Centre

The Dementia Centre provides bespoke consultancy and hosts a rich repository of publications and resources to share its unique philosophy and knowledge. It aims to keep people with dementia at the heart of design and research processes, learning from the stories and experiences of people living with dementia.

HammondCare is an independent charity. In Australia, we operate residential aged care, community care, health and hospitals services. These services include palliative care, pain care, rehabilitation and older persons' mental health, dementia care and supportive care for frail older people. In addition, HammondCare manages over 100 independent living units (ILUs). HammondCare's expertise in dementia care and our highly regarded dementia specific services set us apart in this area. Dementia is a core element of our business in clinical education, practice, service provision, research and academic fields. In 1995, the Dementia Centre was founded by HammondCare as an impartial resource and provider of education, research and evidence-based expertise. This hub for global partnerships has developed significant relationships and knowledge exchange partnerships with world leaders in dementia care and research.

The Centre, now with a dedicated UK team, delivers a wide range of initiatives to support people living with dementia. Other significant service delivery initiatives include Dementia Support Australia. This is a national partnership, funded by the Australian government and

led by HammondCare that brings together dementia expertise from across the aged care industry. The service supports people with dementia experiencing stress and distress, and helps unpaid carers and care staff, including nursing, medical and allied health professionals, understand and respond to changed behaviour.

The Dementia Centre provides bespoke consultancy and hosts a rich repository of publications and resources to share its unique philosophy and knowledge. It aims to keep people with dementia at the heart of design and research processes, learning from the stories and experiences of people living with dementia. We have academic partnerships with universities in Australia and the UK. We also produce reports, social media content, case studies, books and e-publications, and have our own publications team. We have a number of university and industry partnerships in the UK covering discreet knowledge areas. We are also pioneering new virtual reality applications.

Appendix One

Research team



Dr Julie Christie

Service Manager International, Dementia Centre, HammondCare

Julie has experience of working with people living with dementia as a nurse, social worker and social work manager; and has a PhD in the subject of resilience and dementia.

She has worked across a range of settings, including integrated health and social care, residential, care home and hospital sites, and has extensive knowledge on co-production, assessment, risk enablement, self-directed support, and issues of support and protection.

Julie was an associate with the Dementia Centre at the University of Stirling for 10 years and has published work on ethical practice in research, acute hospital care and forthcoming work on resilience in the context of dementia. She is a member of the Scottish Dementia Research Consortium, the 'Centre for Research on the Experience of Dementia' group (University of Edinburgh), and the 'Citizenship and Dementia International Research Forum'.

Julie is Adjunct Lecturer at the University of New South Wales and a Visiting Research Fellow with the University of Edinburgh. Julie's work is focused around citizenship, co-production, and issues that impact on recognition including emerging issues on digital citizenship in the context of dementia. Julie is co-founder of the dementia PhD twitter community #demphd which has created a social media space for people with dementia, researchers and those interested in dementia. Julie has also been working on exciting virtual reality applications that assist in our understanding of the experience of dementia.

Julie is currently working on a practice framework that enables social workers to recognise the resilience of the person living with dementia and related publications in this area.



Oonagh Thompson-Bradley

Senior Project Officer UK and Europe, Dementia Centre, HammondCare

Oonagh is an experienced researcher and project manager, having worked for over ten years on ageing and dementia projects, primarily in Northern Ireland.

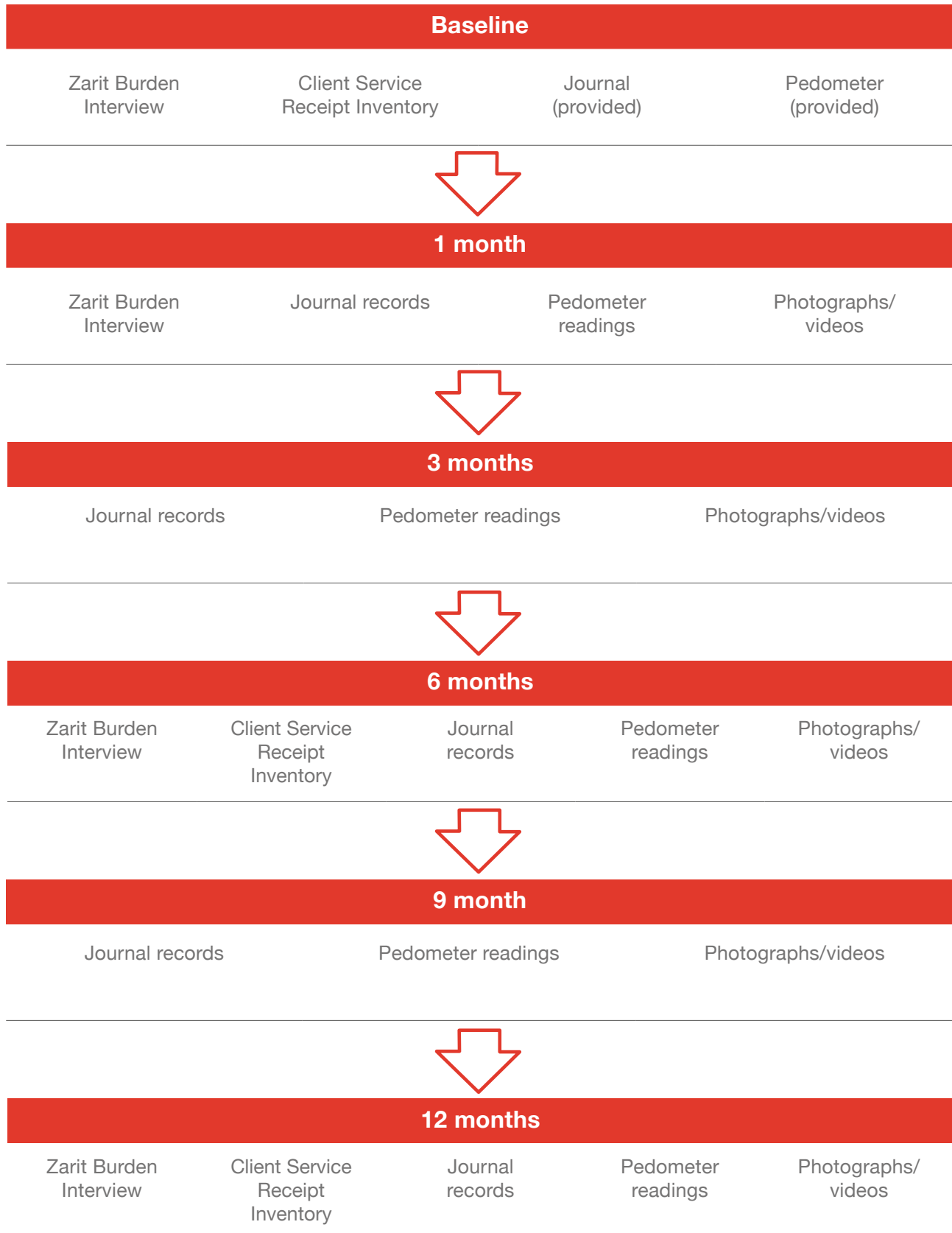
Before joining the Dementia Centre, Oonagh led the Northern Ireland Hospice's Dementia Collaboration to develop an innovative, collaborative model of dementia care and support, aimed at improving the lives of people with dementia, their families and carers in the community. From 2007-2010, she worked to establish and develop the Northern Ireland office of the Dementia Services Development Centre, University of Stirling.

Oonagh holds an MPhil from Queen's University Belfast through which she explored the scope of smartphone-based puzzle games to maintain cognitive health in ageing. In 2011, she spent six months as a Marie Curie early stage researcher with a home care provider in Athens, Greece on a European Commission project (Value Ageing, www.valueageing.eu), researching issues around consent of older people living with support and the ethical implications of eHealth/telemedicine. Oonagh has had the privilege to present, both locally and overseas, and has authored and co-authored several publications.

Outwith the ageing sector, Oonagh has conducted and managed research within primary and secondary education and on advocacy and resilience within the victims and survivors sector in Northern Ireland.

Appendix Two

Dementia Assistance Dog Programme: evaluation schedule



Appendix Three

Data gathered to December 2019

Couple	Baseline	1-month	3-month	6-month	9-month	12-month
Couple 1	Carer burden ² ; service use ³ ; physical activity	Carer burden; physical activity; journal records	Placement ended			
Couple 2	Carer burden; service use; physical activity	Carer burden; physical activity; journal records	Physical activity; journal records	Postponed*	Carer burden; service use; journal records	
Couple 3	Carer burden; service use; physical activity	Carer burden; physical activity; journal records	Physical activity; journal records	Carer burden; service use; physical activity; journal records		Carer burden; service use; physical activity; journal records
Couple 4	Carer burden; service use; physical activity	Placement ended				
Couple 5	Carer burden; service use; physical activity	Carer burden; physical activity; journal records		Carer burden; service use; physical activity; journal records		Carer burden; service use; physical activity; journal records
Couple 6	Carer burden; service use; physical activity	Carer burden		Carer burden; service use; physical activity; journal records		Carer burden; service use; physical activity; journal records
Couple 7	Carer burden; service use; physical activity	Carer burden		Carer burden; service use; physical activity; journal records		Carer burden; service use; physical activity; journal records
Couple 8	Carer burden; service use; physical activity	Carer burden		Carer burden; service use; physical activity; journal records		Carer burden; service use; physical activity; journal records
Couple 9	Carer burden; service use; physical activity	Carer burden	Placement ended			
Couple 10	Carer burden; service use; physical activity	Carer burden		Carer burden; service use; physical activity; journal records	Placement ended	
Couple 11	Dog placed outwith evaluation timescale; placement ended					

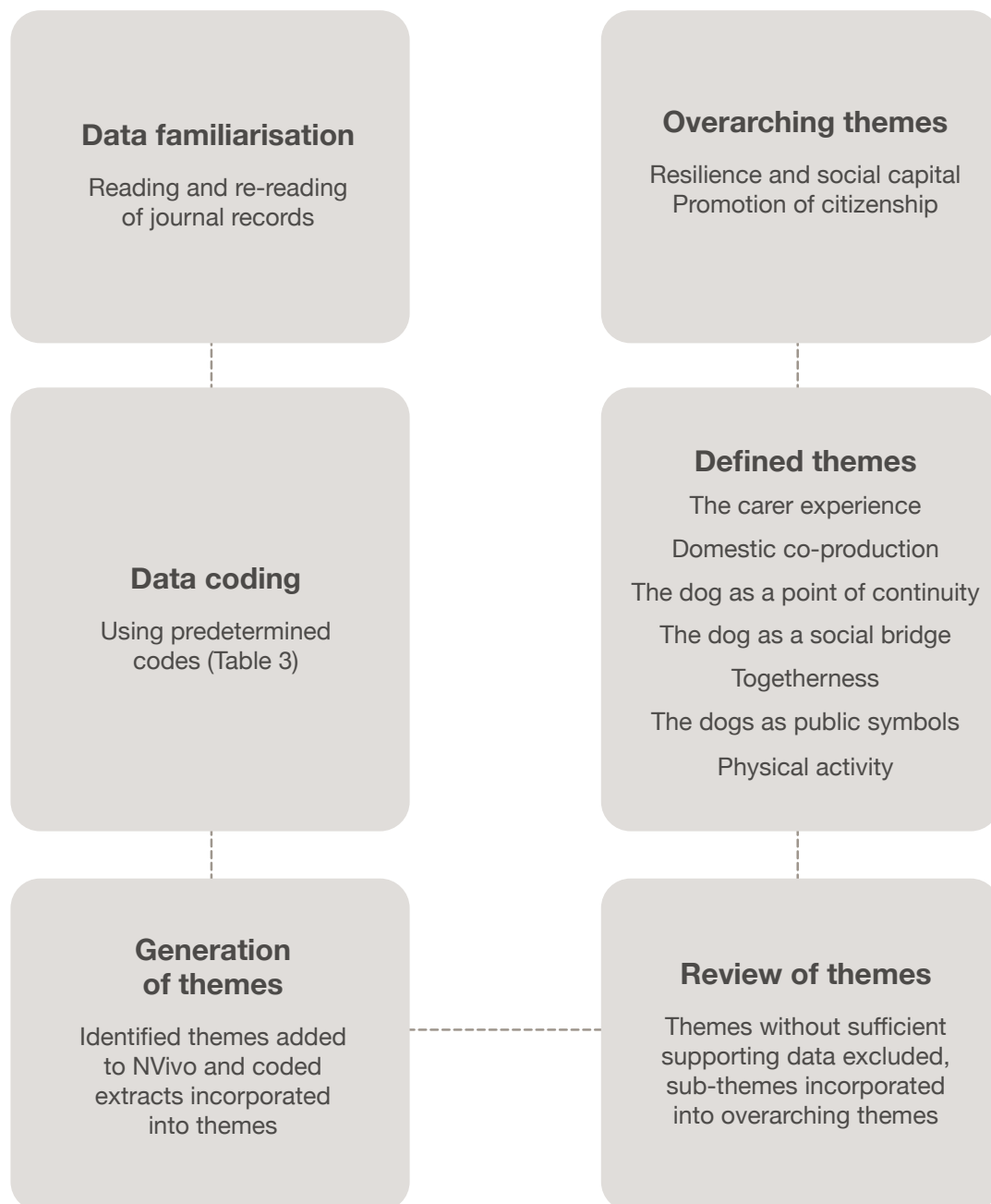
*Person with dementia was ill and in hospital; 6-month data collected at the 9-month time point

² Carer burden was assessed using the short-form Zarit Burden Interview

³ Service use was recorded using the standardised Client Services Receipt Inventory

Appendix Four

Journal data analysis



Appendix five

Short Form Zarit Burden Interview caregiver burden scores

	Baseline	1 month	6 months	12 months
Carer 1	24	27	-	-
Carer 2	10	15	24*	20
Carer 3	15	14	16	24
Carer 4	28	-	-	-
Carer 5	20	19	11	14
Carer 6	9	8	16	10
Carer 7	27	30	29	31
Carer 8	5	6	9	9
Carer 9	2	5	-	-
Carer 10	10	8	14	-

*Person with dementia was ill and in hospital; 6-month data collected at the 9-month time point



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