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

"Webb has made such a difference in both my dad and my mum's life. Not only does he give practical help, but Webb also brings a smile to my Dad's face, something that we rarely see otherwise.

Thank you to all those involved in training Webb, words cannot express just how much he has improved our lives and how much he means to us."
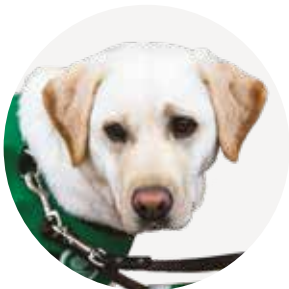
Introducing

Name: Webb
Age: 3 years old

Name: Willow
Age: 3 years old

Name: Hope
Age: 2 years old

Name: Lenny
Age: 2 years old

Name: Uno
Age: 3 years old

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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 to date on the evaluation of the assistance dog programme for people with dementia in Scotland. The work is being undertaken by the Dementia Centre, HammondCare. You can learn more about us and our research team in Appendix One.

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. The section which follows describes the current Dementia Assistance Dog Programme and summarises learning from previous evaluations.

The second part of the report sets out the evaluation standards for this current programme. We then discuss the story of the initiative to date, describing what we have done and introducing the dogs and their locations. In the Appendices, you can find details of the research team, a summary of evaluation findings and the current programme pathway.

We hope you enjoy our introduction to this important work.

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. 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.

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 care partner.

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 care partner. 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 care partner, 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 care partner 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

10am   11am   12noon   1pm

wake up   time to eat

2pm   3pm   4pm   5pm

hydration time   walk me
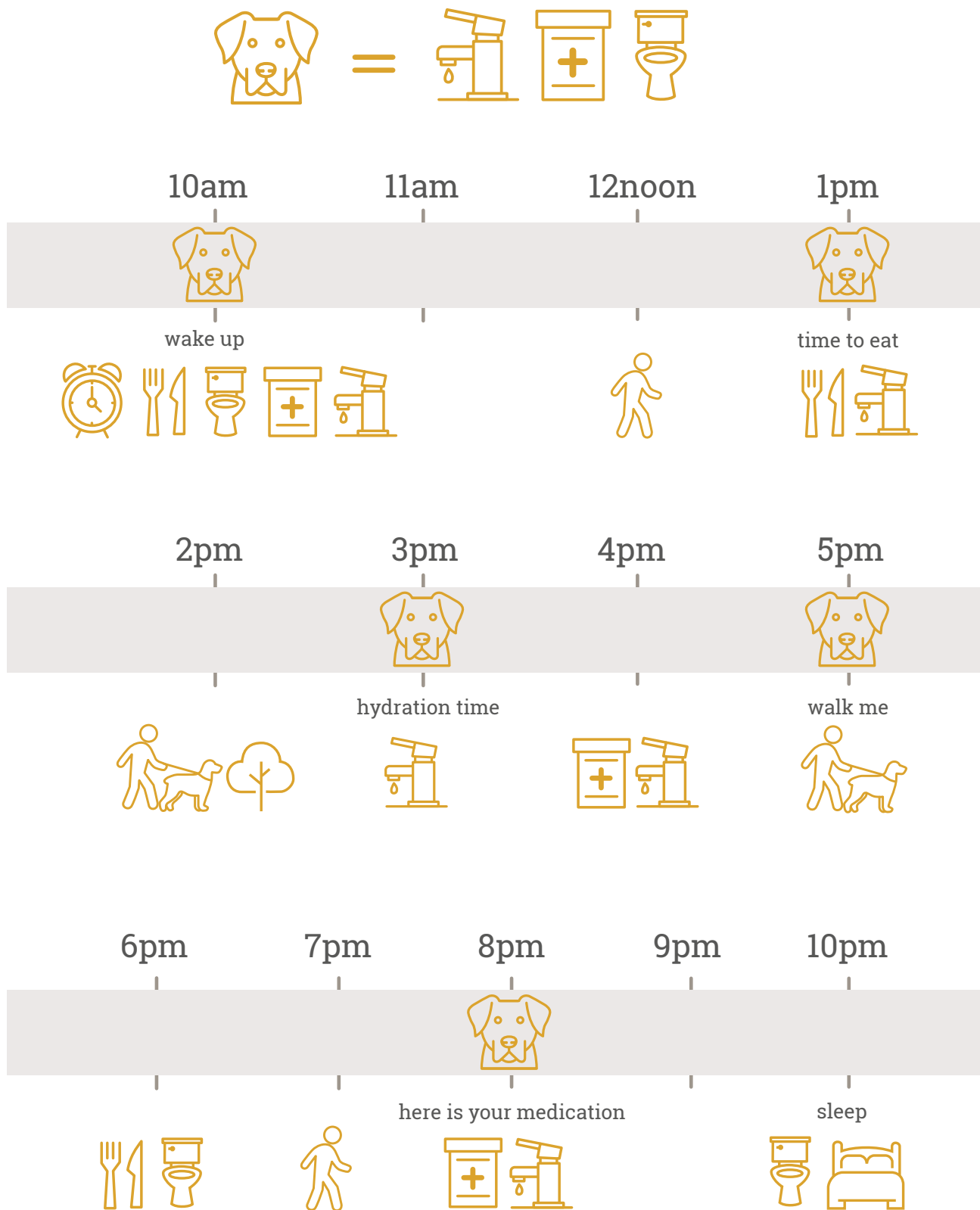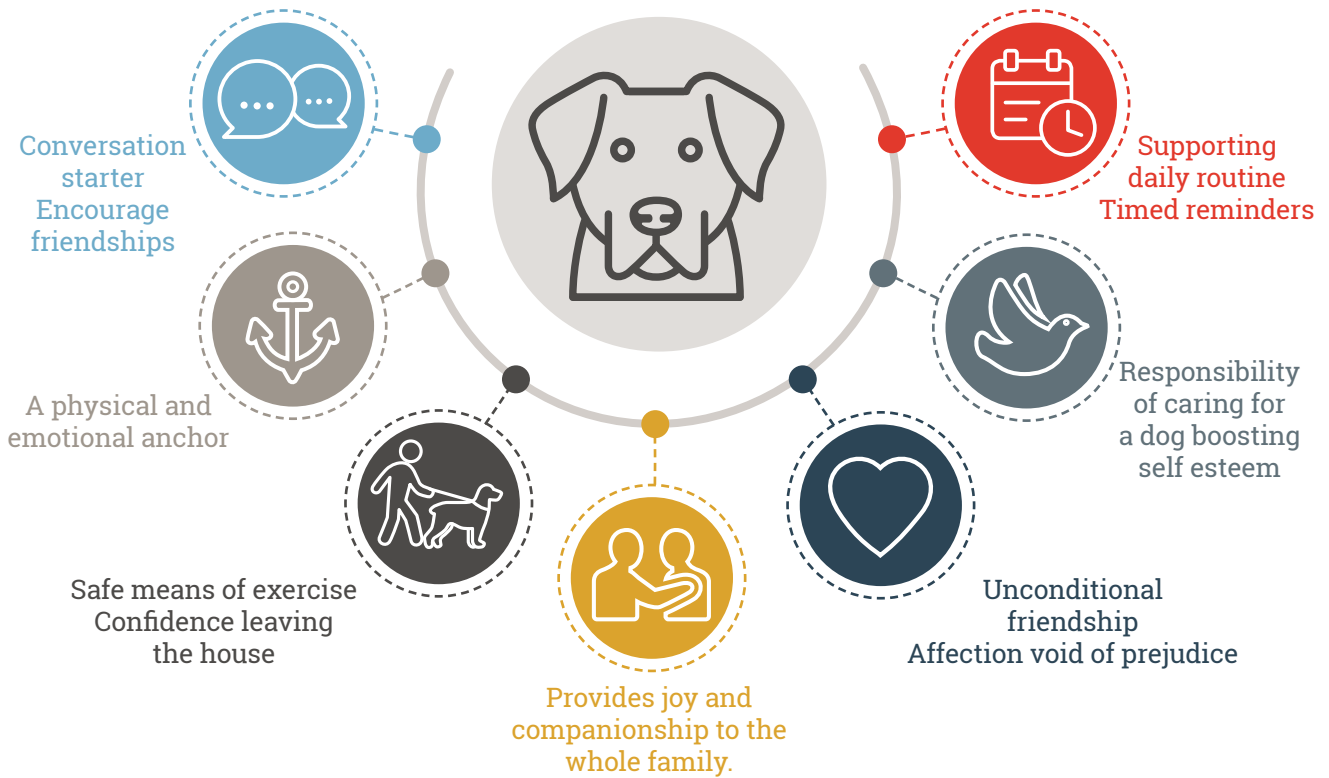
6pm   7pm   8pm   9pm   10pm

here is your medication   sleep

Figure 1. How an Assistance Dog can help to restructure routine within the home.

The expected benefits

Conversation
starter
Encourage
friendships

A physical and
emotional anchor

Safe means of exercise
Confidence leaving
the house

Provides joy and
companionship to the
whole family.

Supporting
daily routine
Timed reminders

Responsibility
of caring for
a dog boosting
self esteem

Unconditional
friendship
Affection void of prejudice

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.

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.

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.

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.

Independence

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

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.

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 care partner. 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, 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. Participating students under custodial care complete an introductory

dog training and welfare course run by Paws for Progress. Students then work with the on-site Dementia Dog Project team to support the training of dementia assistance dogs.

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. The following sections summarise each project and corresponding evaluation. This information has helped to shape the evaluation of the current programme and this is discussed in section 4b. You can also see a summary table of previous evaluations in Appendix Two.

Dementia Dog Project: Phase One

The initial Dementia Dog Project

The initial Dementia Dog Project ran from 2012-2015 in Angus, Scotland. Four couples (a person living with dementia and their care partner) living in the community received a fully trained assistance dog. Three of the four couples established successful partnerships with their assistance dogs. One couple withdrew from the project before the six-month time point due to reported behavioural issues associated with the assistance dog.

An evaluation of the project by an economic and social research consultancy organisation based in Glasgow focused on the impact that the assistance dog had on the couple in terms of physical activity, quality of life and carer support. Data were collected before the dog was placed with the couple and at several points throughout the project, primarily using activity monitors, interviews and carer diaries.

It was planned that all participants would wear an activity monitor for seven consecutive days to collect data including number of steps taken, the intensity of activity (rate of steps per minute) and patterns of activity (also identifying time spent sedentary).

Quality of life was assessed using the Quality of Life in Alzheimer's Disease (QOL-AD) measure[1]. This involved interviewing both the person with dementia and care partner about the person with dementia's quality of life.

Carer support was assessed via a diary kept by the carer. The diary entries indicated the time spent providing support to the person living with dementia over a 24-hour period in relation to supervising, communicating, transport, dressing, eating and appearance.

A limitation of this evaluation is that it did not report on the methodology used to analyse the quantitative or qualitative data, nor how key conclusions and findings were drawn. The number of couples with assistance dogs involved was also very small.

1. Logsdon, R. G., Gibbons, L. E., McCurry, S. M., & Teri, L. (1999). Quality of life in Alzheimer's disease: patient and caregiver reports. Journal of Mental health and Aging, 5, 21-32.

Reported outcomes

This evaluation reported that the assistance dogs supported the people living with dementia in their study in the following ways:

- Emotionally, by offering unconditional companionship and affection;
- Remaining independent for longer due to the responsibility of caring for the dog and a boost in self-esteem;
- Living at home for longer;
- Being kept safe by physical 'anchoring';
- Remaining sociable – attending social activities, meeting friends and going on holiday;
- Preventing crisis support interventions;
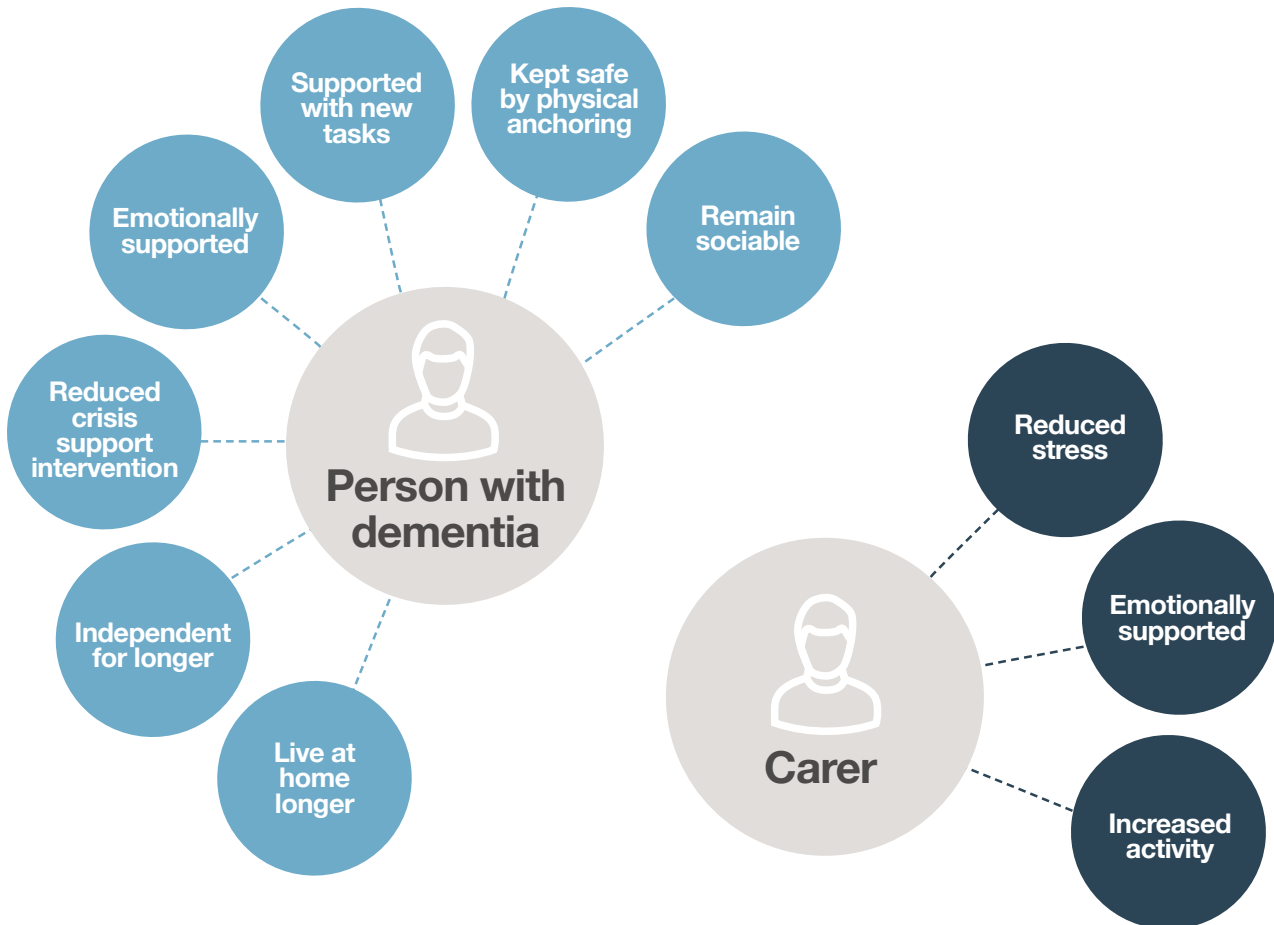- With new tasks as the illness progressed.

The evaluation also reported that the assistance dogs supported carers:

- Emotionally, by offering unconditional companionship and affection;
- Physical health – the carer is the main person to walk the dog;
- By reducing stress, knowing that the person living with dementia is safe.

Generally, the evaluation report concluded that:

- The benefits received from the assistance dogs did not diminish as the person's dementia progressed during the period of this study;
- Quality of life improved (the authors note that, as the illness progresses, the person living with dementia may not interpret and answer the quality of life assessment in an accurate way and so the findings may be unreliable);
- The couples found the emotional and social benefits associated with the assistance dog to be of greater value than the task-based support;
- The impact of the assistance dogs on physical activity levels were not as great as initially anticipated. However, there were 'clear physical health benefits for two carers', i.e. successfully maintaining an increase in activity levels from baseline and continuing to undertake activity at a level and intensity that was deemed to be beneficial to health;
- Having an assistance dog did not increase the activity levels for the person living with dementia.

Reported outcomes: summary

Person with dementia

- Supported with new tasks
- Kept safe by physical anchoring
- Emotionally supported
- Remain sociable
- Reduced crisis support intervention
- Independent for longer
- Live at home longer

Carer

- Reduced stress
- Emotionally supported
- Increased activity

Benefits did not diminish as dementia progressed.
Emotional and social benefits of greater value than task-based support.

For reference, an additional evaluation of the initial Dementia Dog Project was undertaken by the University of the West of Scotland, between February 2016 and February 2017. The aim of the project was to develop an understanding of the contribution dementia dogs can make to living well with dementia. This project focused on the secondary data collected by the team throughout the course of the pilot project and did not include the project participants. The report concluded that the dementia assistance dog programme may provide clearer benefits if it is an ongoing project and that there is a need for more research which looks at the role of dogs within dementia care, with a specific focus on people living in the community.

Dogs 4 Dementia

Dogs 4 Dementia

Following the success of this first Dementia Dog Project and an ongoing partnership between Scotland and Australia, Dogs 4 Dementia was launched in Australia in 2015. The project was funded by the Australian Government Social Services Department. Consultants from the Dementia Centre, HammondCare provided expert dementia advice and support and partnered with trainers from Assistance Dogs Australia to train, match and place assistance dogs with couples living in the community within New South Wales, Victoria, Queensland, South Australia and Tasmania. Ten assistance dogs were placed with ten couples, with six couples establishing successful partnerships with their dogs. Four couples withdrew from the project; two after one month, one after three months and one after six months. Reasons for withdrawal related to rapid changes in the health status of the person living with dementia.

An evaluation by the Dementia Centre, HammondCare aimed to evaluate if 'support from a specifically trained Dementia Dog improves the life of a person with dementia and their carer and allows them to remain living at home for longer, by reducing carer burden and improving overall quality of life'. Both quantitative and qualitative data were collected before the dog was placed with the couple and at several time points throughout the project. Information was primarily gathered by way of questionnaires, journals, calendars of activities and cameras for recording interactions between the person living with dementia and the dog. Seven questionnaires were initially used with participants, gathering information relating to carer burden, depression, anxiety, agitation, quality of life, cognitive ability and service use. Twelve months into the project, a review of the methodology concluded that this number of questionnaires was both burdensome for the participants and unnecessary for the evaluation. The number of questionnaires was reduced to three, enabling the research team to focus on carer burden, depression and anxiety.

Final data were gathered in November 2017.

Reported (preliminary) outcomes

Preliminary analyses of data gathered from four couples indicated a high level of caregiver burden at the beginning of the project. At one-month follow-up, carer burden had decreased to just below the threshold indicated for high carer burden. Carer burden refers to the negative impact of caring experiences.

Emerging themes from participants' journal records and other data sources indicated:

- Greater feelings of safety and security for the person living with dementia, when alone in social situations or when home alone;

- Companionship from the assistance dog for the person with dementia and for the carer;

- Improved emotional wellbeing for the person living with dementia and their carer – the assistance dog brings joy and comfort;

- Increased confidence for the person with dementia to engage in social activities (they are often prompted to talk about the assistance dog);

- Increased confidence for the carer to leave the person living with dementia at home alone;

- Increased physical activity levels for the couples;

- Increased social contact by people in public with the couples.

Researchers found that task-based support was not utilised as much as the training team had anticipated and that the assistance dog's role in providing emotional and social support was of more value to the participating couples. This support for the family was maintained even where the person's dementia had significantly progressed.

Comparison of reported outcomes
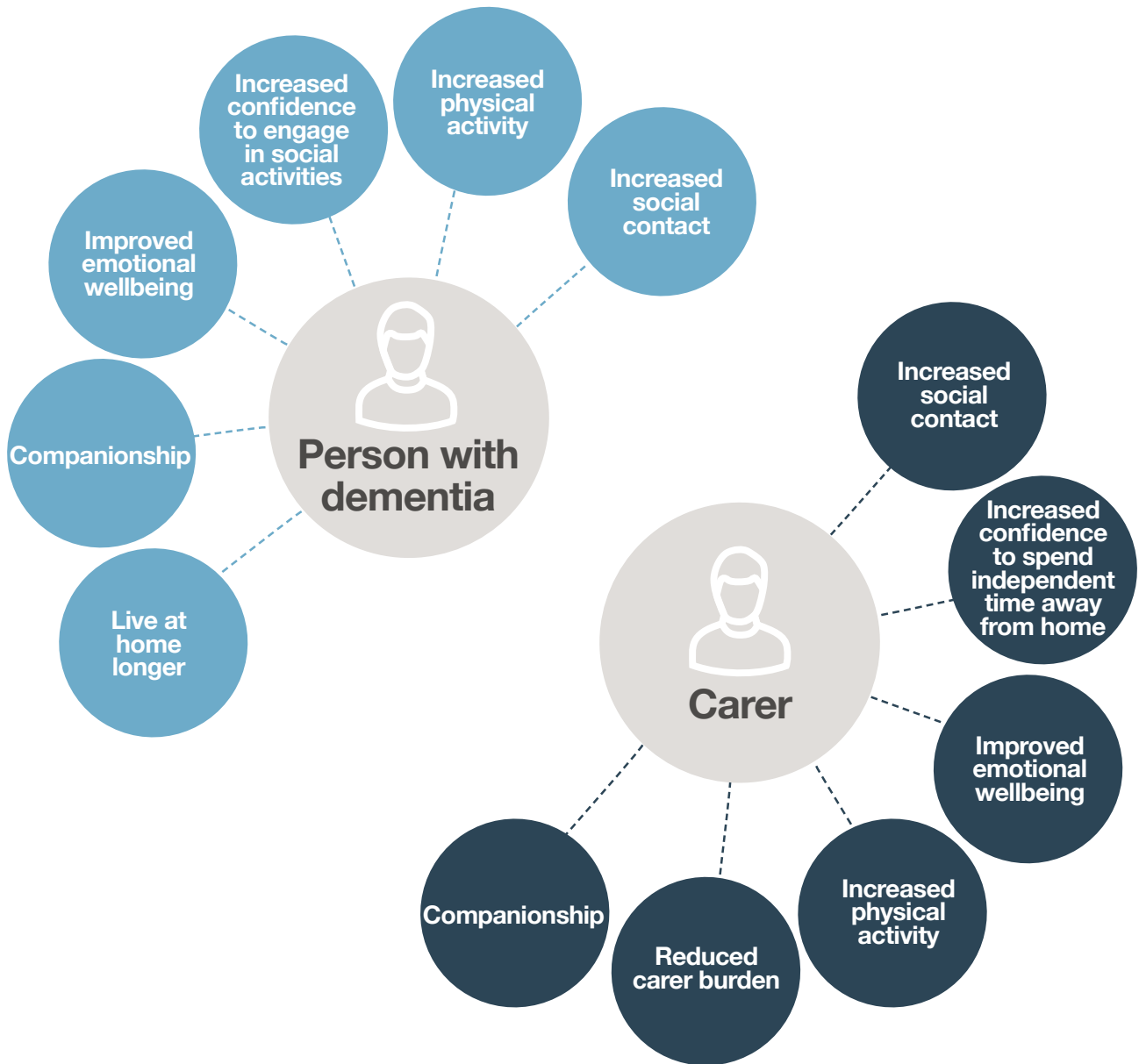
Dog continued to provide emotional support to family even when dementia severely progressed. More emotional and social benefit from assistance dog than task-based support.

As with all small scale evaluations, these findings should be interpreted prudently. The Dementia Dog Project evaluation report did not report details about how data were analysed and subsequent conclusions drawn. As a result, it is difficult to state how rigorous and reliable the evaluation of these data was.

Comparison summary

Physical activity

Both projects reported increased physical activity levels for carers, with Dogs 4 Dementia extending this finding to include the people living with dementia. Analyses were limited by a lack of physical activity data within the Dementia Dog Project (complete data were gathered for only one couple) and so conclusions around activity levels are speculative.

Independence, support and quality of life

The Dementia Dog Project indicated that the presence of an assistance dog enabled the person living with dementia to remain at home and to be independent for longer. The evaluation indicated that the assistance dog prevented the need for crisis support interventions and supported the person with dementia with new tasks as the disease progressed. Additionally, the report stated that 'there have undoubtedly been quality of life improvements for the PWD [person with dementia] and carer'. This finding should be interpreted cautiously due to the small sample and limited reporting of the method of analysis for the Quality of Life in Alzheimer's Disease (QOL-AD) data.

Preliminary data analysis from the Dogs 4 Dementia project indicated that the assistance dog increased the confidence of the person living with dementia to engage in social activities, as well as increased confidence for the carer to spend independent time away from the home. Further, comprehensive analysis should provide greater clarity on the impact of the assistance dog in relation to independence, support and quality of life.

Emotional support

Both projects reported that the assistance dogs emotionally supported both the person living with dementia and their carer. The Dementia Dog Project evaluation reported that unconditional companionship and affection of the assistance dog provided emotional support. Preliminary Dogs 4 Dementia findings reported that the assistance dog brought comfort and joy to the couples.

Emotional and social benefits vs. task-based support

Feedback from the participating couples in the Dementia Dog Project indicated that they found the emotional and social benefits associated with the assistance dogs to be of greater value than the task-based support. This finding is supported by preliminary feedback from the Dogs 4 Dementia project which reported that task-based support provided by the assistance dog was not utilised as much as initially thought and instead the dog provided social and emotional support.

Comparison summary

Carer support and carer burden

The Dementia Dog Project reported that the assistance dogs helped to reduce carer stress due to the carer feeling more confident that the person living with dementia was safe. This evaluation did not report data on time spent by the carer providing support to the person with dementia over the course of the project. Therefore, the impact of an assistance dog on the level of task-based support provided by the carer to the person living with dementia is inconclusive.

Preliminary carer burden data from the Dogs 4 Dementia project indicated that carers experienced high carer burden at the beginning of the project. One month following the dog's placement, carer burden had dropped to just below the threshold for high carer burden.
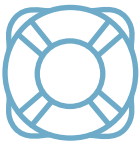
Safety

Both evaluations reported that the presence of an assistance dog supported the person living with dementia to feel safe. The Dementia Dog Project indicated that the person living with dementia felt safer, with the assistance dog acting as a physical and emotional 'anchor' for the person. Similarly, preliminary Dogs 4 Dementia data reported that the assistance dog evoked greater feelings of safety for the person living with dementia.

Socialising

Findings from both projects indicated that the person living with dementia either remained sociable or became more sociable as a result of the assistance dog's presence. The preliminary Dogs 4 Dementia data indicated that the person living with dementia had increased confidence to engage in social activities and that the couples received more social contact when out and about with the assistance dog. Additionally, the data indicated that the carer had increased confidence to leave the person living with dementia at home alone.

Maintained benefits

The Dementia Dog Project evaluation reported that the benefits associated with having an assistance dog did not diminish as a person's dementia progressed. The report did not go into any further detail. This finding is, however, supported by feedback from the Dogs 4 Dementia project – even as a person's dementia progressed, the assistance dog provided emotional benefits to the person living with dementia, their carer and wider support network.

Pictured: Webb rolling out yoga matt for Malcolm

Developing an evaluation framework

Findings from both the Dementia Dog Project and Dogs 4 Dementia project were used to develop an evaluation framework for the second phase Dementia Assistance Dog Programme in Scotland.

Eight fully trained assistance dogs will be placed with eight participating couples living in the community. The aim of the evaluation is to explore and measure how assistance dogs can help people to live well with dementia. Data will be collected before a dog is placed and at multiple time points thereafter (1, 3, 6, 9 and 12 months following a dog's placement).

Following learning from the two previous projects, the Dementia Assistance Dog Programme team was careful to limit carer burden during the data collection process and chose a selective number of assessments and data collection techniques. The assessments focus is on measuring reported carer experiences and carer burden, service use and physical activity, whilst qualitative data will be collected through journals, video recordings and follow-up interviews. In contrast to the previous projects, the Dementia Assistance Dog Programme will focus on the cost of services used by participating couples. In the current economic and political climate, it is essential that new innovative services can not only highlight their physical and social benefits for individuals, families and communities, but also their cost effectiveness. The details are provided in Appendix Three.

The overall aim of the project is 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 carer and the person living with dementia. The data collected may also be 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. Data analysis will be thorough and rigorous and clearly reported to easily enable comparisons with future projects and results replication. The evaluation will 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.

The story so far

Enquiry outcomes

By July 2018, five dogs had completed the full training programme to become dementia assistance dogs. At this point, the programme had received a total of 34 enquiries. Of these, five couples were successful in their applications to receive an assistance dog. Enquiry statics, including reasons for applications not progressing, are detailed in Figure 2.

- Dog team decided not to progress
- Live applications
- Dementia too progressed
- Successful applications
- Family decided not to progress
- Illness / health issues
- Problems completing enquiry form
- No dog available on application
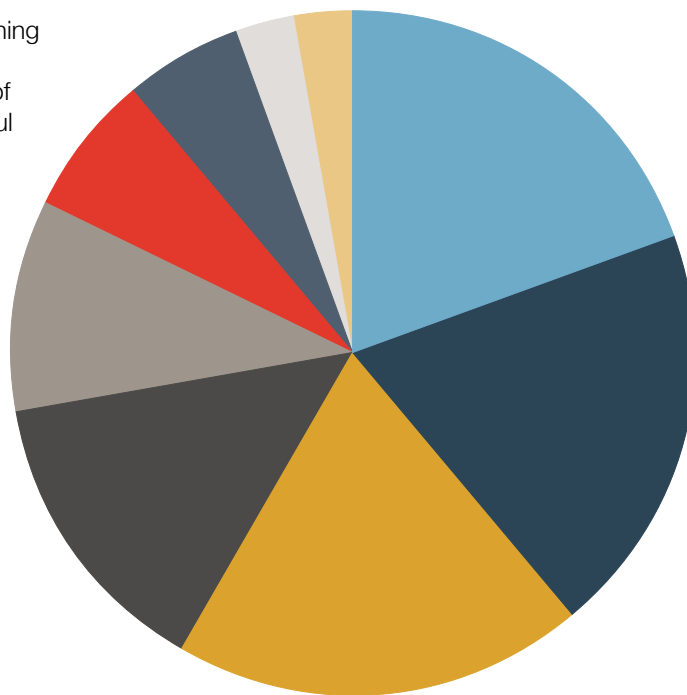- No diagnosis of dementia

Figure 2. Enquiry outcomes from the Dementia Assistance Dog Programme

Within the current programme, five couples have had dogs placed with them, three of which are active (continuing) placements. The status of each couple is detailed in Table 1. Couple 1 withdrew from the programme 11 weeks after the dog was placed as a result of ill health of the care partner. Couple 4 withdrew from the programme six days after the dog was placed because the person with dementia and assistance dog were not forming a bond.

Table 1. Placements within the current Dementia Assistance Dog Programme.

Couple	Area	Dog placed	Placement date	Status
Couple 1	Perth & Kinross	Dog A	14 June 2017	Withdrawn
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	Withdrawn
Couple 5	Glasgow	Dog A	17 May 2018	Active

Placements by location

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

Kirkwall

Thurso

Stornoway

Inverness

Aberdeen

Fort William

Dundee

Perth & Kinross

St Andrews

Fife

Glasgow

Edinburgh
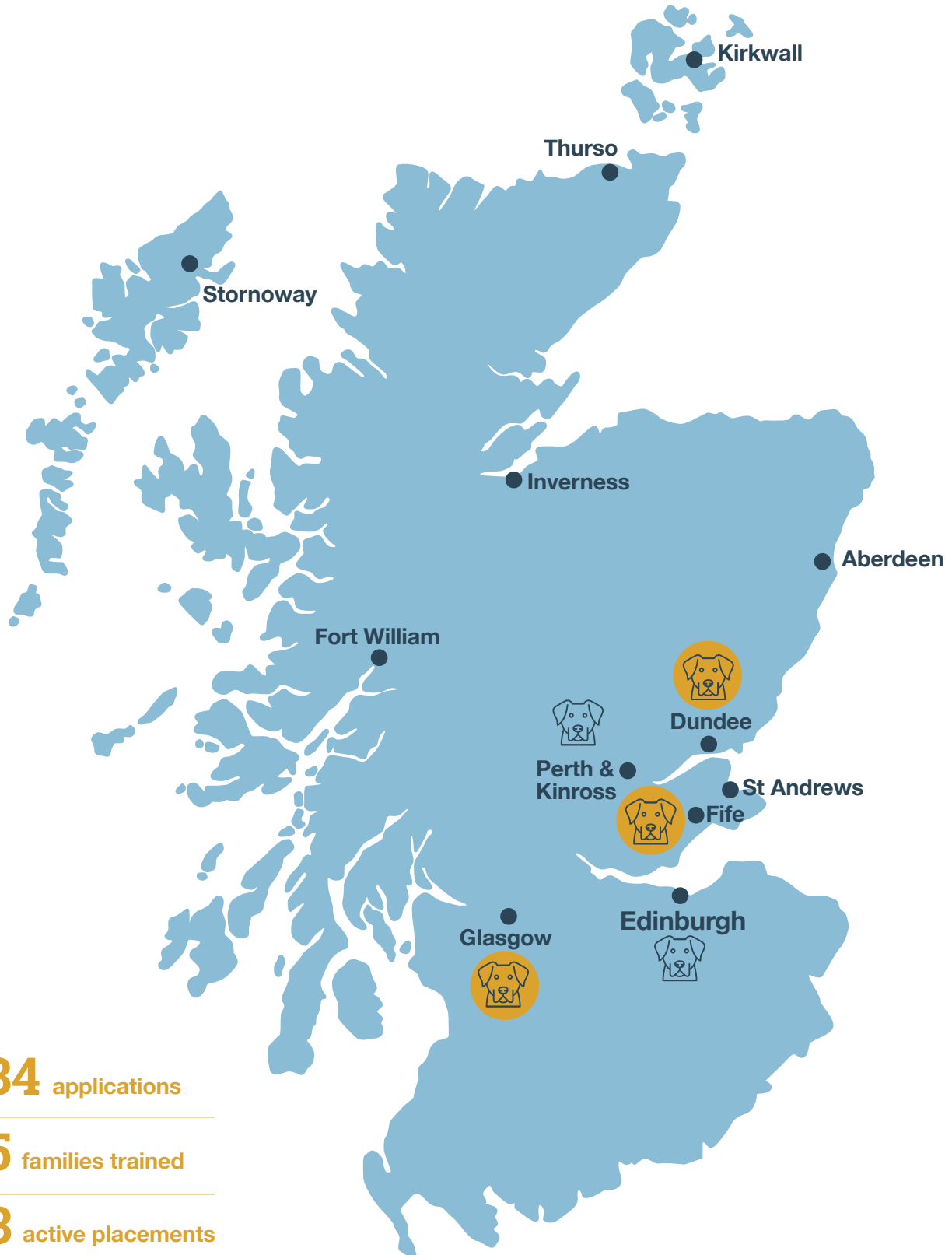
34 applications

5 families trained

3 active placements

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, it was decided that, for new couples, the Dementia Centre, HammondCare would assume this task. This change is 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. Provision of this support will be reviewed as part of the evaluation.

Data gathered to date are summarised in Table 2.

Table 2. Dementia Assistance Dog Programme: Data gathered by July 2018.

Couple	Baseline	1-month	3-month	6-month	9-month
Couple 1	Carer burden; service use; physical activity	Carer burden; physical activity; journal records	Withdrawn		
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	
Couple 4	Carer burden; service use; physical activity	Withdrawn			
Couple 5	Carer burden; service use; physical activity	Carer burden; physical activity; journal records			

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

The questionnaires within this evaluation capture information about carer burden and service use, pedometers measure physical activity, while journals, video recordings and follow-up interviews gather insights into the impact the assistance dog has on independence, quality of life, social activity, emotional support and safety.

Data analysis will focus on how assistance dogs can support 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. The information gathered may be used to discuss 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.

The evaluation will also examine the cost of services used by participating couples with a view to considering the cost effectiveness of an assistance dog programme for people living with dementia.

The evaluation will identify both the benefits and challenges associated with an assistance dog programme, to ensure a balanced view and to enable future projects to develop the concept further.

Cost of assistance dogs

The average organisational costs for provision and life time support of a dementia assistance dog is £21,500. This can be broken down as follows:

- Training costs 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 – £8,000

With regard to this programme the costs for five assistance dogs is approximately £67,500, with a further £40,000 in ongoing support costs. This is a total cost of £107,500.

Case study: Webb's story

Little did Webb know, as an eight week puppy, just what a special future he had ahead. Having completed his first year of socialisation, he commenced early training with the Dogs for Good team at their Oxfordshire headquarters. It was then that Webb was identified as having the perfect temperament and skills for the Dementia Dog Project.

Webb arrived to Scotland at the start of 2017 to complete his advanced training, where he began to learn specific skills to help someone with dementia. Here, with the added help from men in custody at HMP Castle Huntly prison, he learnt how to respond to an alarm to fetch medication, wake someone up in the morning, open and close doors and walk on a dual lead.

Webb has gone on to use all these skills and more with his new family, Imke and Malcolm, that he was matched and placed with in September 2017.

Malcolm was diagnosed with dementia associated with Parkinson's in 2016, which can present a number of daily challenges for both himself, and his wife and full-time carer Imke. Webb quickly settled into his new home as part of the family, forming strong bonds with both Malcolm and Imke. Many of the skills he learnt are now used on a daily basis.

Imke explains, "Webb helps in all sorts of practical ways – fetching medication, taking off Malcolm's socks, finding and opening doors and getting us out of the house together. Webb introduces laughter back into the home; in turn Malcolm benefits by Webb giving me the strength to cope. The wonderful people from Alzheimer Scotland have also come into our lives to offer technical support and assistance in accessing practical help."

In addition, recently Webb has been learning how to roll the yoga mat out each morning to motivate Malcolm to do his physio exercises, as well as locating and opening the sitting room door to help Malcolm's orientation.

Webb has also brought joy for the wider family too. Their daughter says, "Webb has made such a difference in both my dad and my mum's life. Not only does he give practical help, but Webb also brings a smile to my Dad's face, something that we rarely see otherwise. Thank you to all those involved in training Webb, words cannot express just how much he has improved our lives and how much he means to us."

Pictured: Malcolm, Imke and Webb

Where to from here?

Two fully trained assistance dogs, Lenny and Hope, are currently awaiting successful applications to the programme and will be placed thereafter. 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

dementiadog.org/

@dementiadog

@dementiadogproject

The Dementia Centre, HammondCare evaluation of the Dementia Assistance Dog Programme will be reported in 2020 when the programme concludes.

Appendix One

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 care partners 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

The team

Dr Julie Christie

Region Manager UK and Europe, 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

Summary of assistance dog project findings

Summary of findings and preliminary findings from the Dementia Dog Project and Dogs 4 Dementia project including how the Dementia Assistance Dog Programme will build upon these findings.

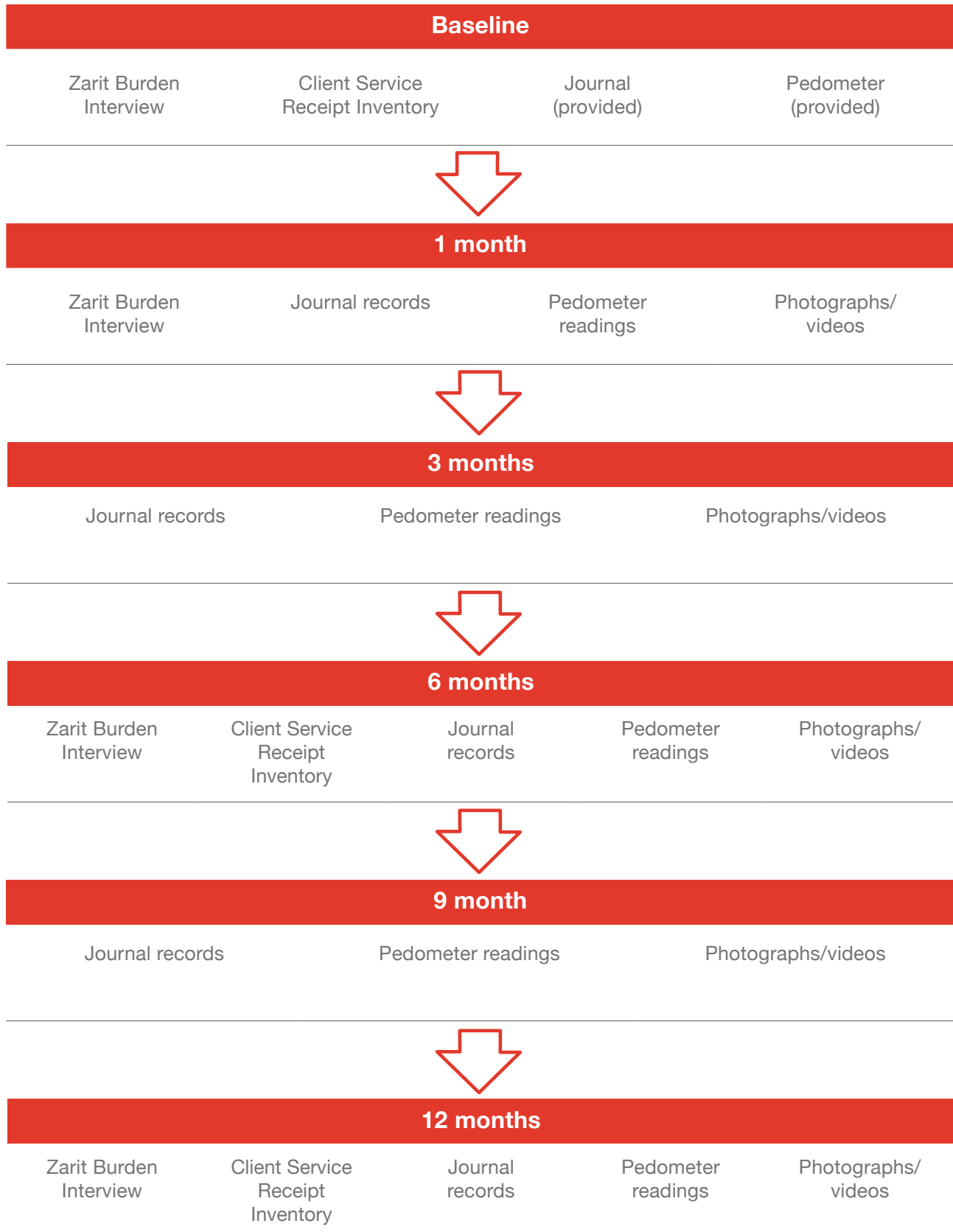| Finding	Dementia Dog	Dogs 4 Dementia	Dementia Assistance Dog Programme
Activity Levels	Increased activity for carer No increased activity for person living with dementia	Increased activity for carer and person living with dementia	Utilise pedometers to collect quantitative data to measure activity levels for the person living with dementia and carers Do not use an activity calendar to collect qualitative data. This will reduce participant burden and biased retrospective completion Larger sample size than first phase of Dementia Dog project will enable greater reliability and validity of findings
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	Journals and video recordings will provide a rich insight into the impact of the assistance dog on independence, support and quality of life Utilising both written journals and video recordings to collect data will enable more robust findings or highlight discrepancies between the two methods that can be further investigated during follow-up interviews Follow-up interviews will enable unique individual feedback regarding the impact of an assistance dog on independence, support and quality of life Utilise a validated service cost assessment (Client Service Receipt Inventory) to highlight changes in support services or emergency care Utilise pedometers to track activity level data that may support an increase or decrease in quality of life for the person living with dementia and their carer
Carer Support & Carer Burden	Reduced carer stress	Reduction of carer burden	Utilise a validated carer burden assessment to collect quantitative data (Zarit Burden Interview) Focus on carer burden rather than carer support (how much time the carer spends providing task-based support to the person living with dementia) This decision is based on feedback suggesting that emotional support is greater valued than task-based support Journals, video recordings and follow-up interviews will provide qualitative data regarding carer burden

Appendix Two

Summary of assistance dog project findings

Summary continued

Finding	Dementia Dog	Dogs 4 Dementia	Dementia Assistance Dog Programme
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.	Journals, video recordings and follow-up interviews will provide an insight into the impact of the assistance dog on emotional support
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	Journals, video recordings and follow-up interviews will collect information about the impact of the assistance dog on safety
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	Journals, video recordings and follow-up interviews will highlight the impact of the assistance dog on socialising
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	Journals, video recordings and follow-up interviews will highlight if any benefits associated with the assistance dog are maintained as the dementia progresses
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	Journals, video recordings and follow-up interviews will provide an insight into what aspects of the assistance dog are more greatly valued

Appendix Three

Dementia Assistance Dog Programme: evaluation schedule

Baseline

| Zarit Burden Interview | Client Service Receipt Inventory | Journal (provided) | Pedometer (provided) |

⬇

1 month

| Zarit Burden Interview | Journal records | Pedometer readings | Photographs/videos |

⬇

3 months

| Journal records | Pedometer readings | Photographs/videos |

⬇

6 months

| Zarit Burden Interview | Client Service Receipt Inventory | Journal records | Pedometer readings | Photographs/videos |

⬇

9 month

| Journal records | Pedometer readings | Photographs/videos |

⬇

12 months

| Zarit Burden Interview | Client Service Receipt Inventory | Journal records | Pedometer readings | Photographs/videos |

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