

Life Changes Trust

People Affected by Dementia Programme

Individual Awards Pilot Projects: Argyll & Bute and Edinburgh

Evaluation Report



“...Think laterally if you can.

..And vertically!

.....And diagonally!..”

**Focus group,
Edinburgh**



The Life Changes Trust was established by the Big Lottery Fund with a National Lottery grant of £50 million to drive transformational improvements in the quality of life, well-being, empowerment and inclusion of people affected by dementia and young people with experience of being in care.

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FOREWORD

This evaluation report is based on feedback from people living with dementia and carers who received an Individual Award from the Life Changes Trust. The Individual Awards Pilot Scheme was run in Argyll & Bute and Edinburgh in 2014-15 and aimed to provide a small amount of additional financial empowerment to a number of individuals whose lives have been affected by dementia, to help improve their well-being and quality of life.

A secondary aim of the pilot scheme was to find out what people would spend the Award on when given relatively broad choice, and what benefit that might bring in the short and medium terms.

Adequate financial resources can mean the difference between living well with dementia or struggling to cope with living with dementia. Following a diagnosis of dementia, individuals and families can experience increased financial disempowerment and vulnerability, even when they have been relatively well off in the past. Loss of earnings because the person with dementia or carer has had to give up work can lead to circumstances where income diminishes (often unexpectedly), there are unforeseen expenses and credit is curtailed. Sometimes the wider family is in a position to help out, but often this is not the case and it can be embarrassing to ask for help.

For many households, savings and assets are the critical first line of defence against emergencies, unforeseen expenses, and income interruptions. Families that have adequate savings and assets may successfully weather such setbacks, but households that lack this security are financially vulnerable and at risk of falling into poverty. This evaluation indicates that some people living with dementia in Scotland are living in poverty and for whom an Award of up to £500 has made an enormous difference and will continue to do so for some time.

In addition to the benefits increased financial resources bring, this evaluation highlights the importance of strong relationships, time spent with people and the importance of supporting individuals to talk about what matters to them and what impacts their sense of well-being. It also shows that people can be trusted to spend money wisely when given time and support to think about it.

The report talks about the 'ripple effect' of having received an Individual Award, which goes beyond the immediate benefit of the item or experience purchased. The Awards often helped open up conversations in families or with volunteers that revealed hidden needs - for example, around continence – which could then be addressed. Families and friends discovered the issues that were really worrying people, such as the living room carpet having become so worn that it was embarrassing to invite people to the house, or extreme tiredness impacting a person's ability to be a carer because they did not have a suitable bed. These two examples illustrate how very personal issues can lead to loneliness and isolation or a carer becoming unable to care any longer.

Some of the feedback in this evaluation report might make you laugh and some might make your day more sombre. Every experience related is happening to real people living in Scotland today and there is no reason to believe that what has been reported from these pilots in Argyll & Bute and Edinburgh is not happening in every area across Scotland.

The Life Changes Trust and its advisors will consider the findings of this report and decide what further action should be taken in light of it.

We would like to express our deep gratitude to Janet Stewart of InMind Consultancy for her careful analysis of the feedback received through letters, focus groups and interviews. Her analysis is robust and also brings a sense of real insight and appreciation of what the Individual Awards meant to those who received them.

Anna Buchanan
People Affected by Dementia Programme Director
September 2015

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The Trust would like to thank the following for helping to deliver and evaluation this initiative:

- Supporting partners who helped applicants apply for funding and for the administration of the Awards

Argyll & Bute:

- Crossroads for Carers (Cowal & Bute)
- Dochas Carers' Centre
- Helensburgh & Lomond Carers
- North Argyll Carers
- The Royal Voluntary Service (RVS)

Edinburgh:

- LifeCare (Edinburgh)
- VOCAL
- The Royal Voluntary Service (RVS)
- Minority Ethnic Carers of Older People Project (MECOPP)

- Evaluation support
 - Janet Stewart, InMind Consultancy

- **“I was starting from scratch at about 73 years of age.”**

When his wife developed dementia, Murdo* from Argyll & Bute described himself as taking on a new role as a homemaker and learning a whole new set of skills. He hoped to keep his wife at home for as long as possible and her well-being is very important to him. Now responsible for the housework, as well as caring for his wife, he had begun thinking about how he was going to cope with the future and what needed to change to make everyday household tasks more manageable. When the opportunity of an Individual Award came up it was “a real help and a real incentive to move quickly”. He was able to replace the carpets in the bathrooms with vinyl flooring making it easier to maintain hygiene, and to buy a tumble dryer which had been timely given a period of particularly wet weather. These changes have made a great difference to Murdo, making caring for his wife significantly easier and making things feel more manageable. This has made him feel more positive about his caring role and has helped his emotional resilience.

“It’s proved a boon, I can assure you”.

- **“Now I can go out to the garden whenever I want.”**

Elaine* from Edinburgh, who has dementia, loves being in her garden and used to sit out there with her late husband, but since losing her mobility 18 months ago, has been unable to negotiate the steps into the garden, so it had become inaccessible to her. An Individual Award has enabled ramp access, restoring her freedom to spend time outdoors in her own garden when she chooses. Using her walking aid to reach a seat in the fresh air helps keep up her strength and, as well as spending time outside, she has a renewed interest in the garden and is making plans for some new plants. She is trying to get outside every day and from the garden she can also say hello to the neighbours again. With family coming from abroad to visit later in the year she is now looking forward to spending time in the garden with them.

*Not real names

- **Holidays and insight**

Marianne* from Edinburgh used an Individual Award to take her two children and her mother, who has dementia, for a short break at a hotel in the countryside. Her mother enjoyed the surroundings, good food and was happy to have her grandchildren around her but, being out of her familiar environment, she sometimes got disorientated and confused. Although this was stressful for Marianne, it was really helpful to spend so much extended time together with her mum over those few days as it was a chance to really watch her and think about her changing needs. Noticing that her mum was finding it difficult to eat her meals without getting distracted, Marianne decided to increase her mum's support at home.

The insight gained from that time together helped to make sure her mum's nutritional and other needs continued to be met. It was not necessarily the holiday Marianne had envisaged, but turned out to be a truly invaluable few days in terms of sustaining her mum's health and well-being in the longer term.

“It's really the fact that I'm doing it, you know... I realised that this is probably pretty good for you.”

Since Shona* was diagnosed with dementia, she and her husband James* have been very aware of the importance of keeping active and involved. Their daughter is a member of a health club and had been suggesting for some time that her dad might benefit from more regular physical activity. With the opportunity afforded by the Individual Award, Shona and James decided to take the plunge and join the health club for a year. They go together, usually twice a week, and meet up with their daughter, which is “another big plus” as they really enjoy that time with her and have a light lunch together in the cafe. Then Shona and her daughter go to the pool while James does a session in the gym. Always a sporty person, Shona enjoys the swimming and appreciates her daughter's help with managing the locker in the changing rooms. Recently they have taken things a little further with Shona booking a number of lessons to improve her swimming technique. James finds that when, for some reason, they have to skip a session he really misses it and looks forward to getting back.

The health club outings are a very positive part of their life now, bringing a sense of satisfaction and wellness.

Section 1: The Aims and Spirit of the Individual Awards Pilot

The Individual Awards Pilot was launched by the Life Changes Trust in September 2014 to award sums of money to individuals affected by dementia; that is, **a person living with dementia or a person caring for someone with dementia for more than four hours a week and not being paid to do so.**

Primary purpose

The primary purpose of the pilot was to offer additional financial support to people living with dementia and their carers to enable them to improve their quality of life. This support took the form of a one-off payment of up to £500 per person, with Awards potentially available for anyone fitting the criteria of living within the geographical areas participating in the pilot (Edinburgh and Argyll & Bute) and being affected by dementia. Joint applications could be made (for example by a person with dementia and their carer, or by two carers) for a maximum of £1,000 between two people. Applications could be made between 1st October 2014 and 15th January 2015. Eligibility for the Awards was not income-related or means-tested. The criteria for spending the Awards were deliberately left as broad as possible, so that people could choose to use the money to do anything that:

- **mattered to them;**
- **would make their life better; and**
- **they would be unable to do without the Award**

The intention was that financial empowerment would enable highly personalised action on the part of the Awardee to improve their quality of life. The approach aimed to optimise the level of choice and control for Awardees, while providing practical support for applicants proportionate to their needs so that the Award process did not become too burdensome.

Secondary purpose

The secondary purpose of the pilot was to build knowledge that could be shared about what people felt they could spend £500 on to improve their well-being and quality of life.

The Trust hoped to gain understanding about:

- **the things** people request money for when the funding criteria are wide (i.e. when there are few restrictions as to what the money can be spent on)
- **the benefits**, both in the short and longer terms, that Individual Awards of a relatively small amount of money can bring
- whether the method of working with **local partners** is the most beneficial way to deliver Individual Awards
- **any other insight** or learning that might emerge from the pilot, particularly if this could ultimately improve the lives of people affected by dementia

Evaluation was therefore approached with these key points in mind and bearing in mind that 'benefits' might cover a whole range of outcomes relating to quality of life, including difficult-to-measure, subjective factors such as emotional well-being. Moreover, it was important, where possible, to consider the meaning of particular outcomes for that individual or family in order to create a valid evaluative picture.

As well as exploring immediate benefits for the Awardee, consideration was made of the possible wider impact, both in terms of potential knock-on or 'ripple' effects for the individual and in terms of repercussions for partners, family, the partner organisations delivering the Pilot, communities and society as a whole. This aims to contribute to the bigger picture of the high-level, overall impact of this approach to funding.

Section 2: How the Awards Pilot was Run

The administration of the Awards was managed through the collaboration of partner organisations in the two pilot areas. Argyll & Bute provided the opportunity to pilot the Awards with people living in small town, rural, remote and island locations, while Edinburgh provided a city setting. It was hoped that this might bring to light any particular considerations for implementation in either urban or rural areas.

The partner organisations in the Argyll & Bute area were:

- Crossroads for Carers (Cowal & Bute)
- Dochas Carers' Centre
- Helensburgh & Lomond Carers
- North Argyll Carers
- The Royal Voluntary Service (RVS)

The partner organisations in the Edinburgh area were:

- LifeCare (Edinburgh)
- VOCAL
- The Royal Voluntary Service (RVS)

A smaller pilot was run in collaboration with the Minority Ethnic Carers of Older People Project (MECOPP) in Edinburgh. This focused on people from the South Asian community in Edinburgh and aimed to explore the views and choices of carers or people with dementia who engaged with the Individual Awards Pilot, flagging up any additional considerations which could help ensure the cultural competence of frameworks for financial empowerment.

To control the number of applications received given the very broad criteria, promotion of the Awards scheme was minimal beyond direct promotion to potential beneficiaries by partner organisations and a brief description of the Pilot on the Life Changes Trust website. Partner organisations also had a remit to support applications from anyone who enquired about the Awards, provided they fitted eligibility criteria.

The role of the Trust's partner organisations included:

- informing potential beneficiaries about the Individual Awards pilot
- providing support if required to make an application¹
- coding for anonymity, scanning and emailing applications and equality monitoring forms to the lead partner (RVS)
- making joint decisions at fortnightly Award Panel meetings concerning applications
- following up with Awardees to get receipts which were coded, scanned and sent to the lead partner
- assisting individuals to give feedback about the Awards by completing a guided letter provided by the Life Changes Trust
- sending feedback to the Trust
- participating in partners' meetings in January and June 2015

The lead partner, RVS, was additionally responsible for:

- communicating to applicants the outcome of their application
- keeping notes of meetings and quantitative data records
- assigning a number to the anonymised code on all communication from applicants
- holding the funds and making payments to successful Awardees
- keeping all local Award Panel members informed with a list of successful and unsuccessful applicants (by code), the amount of the Award and what it was to be spent on

It should be noted that the smaller pilot with MECOPP was run through a more devolved model, without the involvement of a lead partner. MECOPP were the grant holders and invited people with relevant expertise from other organisations to sit on their Award Panel, issuing the payments directly to successful applicants and managing the administration processes.

¹ See Appendices A and B for the Application Form and the Applicant Guidance respectively.

As mentioned above, the criteria for the proposed use of the Award were broad, although goods or services which should be received under statutory provision were generally not seen as appropriate. However, this is a difficult issue as statutory provision is not always available.

Award Panels met once a fortnight in each of the pilot areas to consider the applications and decide whether the Award would be granted. If a request was denied, the applicant would be provided with feedback and was invited to submit a second and final application with a different proposed use of the funds. In the event of an applicant's circumstances changing, it was at the discretion of the Panel to accept a proposed change of use for the money, without the person having to repeat the application process.

Payment of the Award to successful applicants was to be made by cheque or BACS no later than three weeks after the Panel's decision. The Awardee's spending deadline was two months from the date of receiving the funds. The partner organisations were responsible for following up with Awardees within three months for receipts and feedback. Guided feedback letters were sent to the Life Changes Trust fortnightly.

Timescale:

- Preparatory work: 2013/14 (in stages, not continuous)
- Launch: September 2014
- Open for applications: 1 October 2014 – 15 January 2015
- Awards provided: November 2014 – March 2015
- All Awards spent by: August 2015
- Evaluation: May – July 2015

Section 3: Evaluation Methodology

The Life Changes Trust provided partner organisations with a standard evaluation tool in the form of a guided feedback letter², which Awardees could either fill in on their own or be helped to fill in either over the phone or face-to-face. Both people with dementia and carers often accepted the support of a Partner (a member of a partner organisation) or of a family member in completing the guided letter. A number of people provided additional feedback in the form of personal letters of thanks or 'before and after' photos. The first stage of evaluation involved analysis of the written feedback from the Awardees. At the time this evaluation report was written, 90% of successful applicants had completed guided feedback letters and more feedback letters were submitted subsequently, which is an exceptional response rate.

Partners made all reasonable attempts to gather feedback. In some cases it was not possible for people to provide feedback due to life events such as hospitalisation, transition to residential care, death or bereavement. In a few cases the Awardee did not respond.

The second stage of the evaluation involved conversations with a small sample of those who had said they would be willing to talk in more detail about their experience of the Pilot. This was done through five focus groups, six face-to-face interviews (two of these were home visits) and seven telephone interviews. The conversations were semi-structured, keeping them as open as possible to allow unpredicted issues to be raised and explored.

A total of 32 individuals participated in this second stage, representing 7% of those who received an Award. The majority of participants were carers – 12 male and 20 female – and most of them were the partner or the son / daughter of the person with dementia, although one person was caring for her daughter. One person with dementia actively participated in giving feedback in this second stage. Three other people with dementia were present during an interview or focus group, but as their carer spoke on their behalf they are not included in the total sample number.

² See Appendix C for a copy of this guided feedback letter.

The feedback suggests that it was important that this second stage was optional and that there was the choice of participating in a group discussion or in an individual interview.

The third stage of the evaluation focused on the perspective of the partner organisations, whose ongoing feedback was received and valued throughout the pilot. Final review meetings between Trust and partner organisations' staff provided an opportunity to retrospectively critique the Pilot, including concept, acceptability, feasibility, outcomes and the most advantageous way to administer it.

However, as many of the people living with dementia involved in the Pilot were in the middle or advanced stages of dementia, the guided letter feedback was often provided jointly by a person with dementia and a carer or was provided by the carer. Feedback was also received from people with dementia, showing that although this may be a challenge, it is possible.

Section 4: Overview of Figures and Finance

Demographic context

At the planning stage, Census 2011 population statistics for Edinburgh and Argyll & Bute were used to inform the original allocation of funds between the two areas for the Individual Awards. The Awards budget was allocated on a per capita basis plus a small weighting was given to Argyll & Bute to reflect the remote nature of the area and the higher percentage of people over 65 or having a caring role. This resulted in an anticipated 28%:72% split of the Awards money between Argyll & Bute and Edinburgh respectively.

In Edinburgh, a complimentary sub-pilot was targeted at the South Asian community, although people from any minority ethnic community could have applied to the general Edinburgh pilot. The largest ethnic minority population in Edinburgh is 'Asian, Asian Scottish, Asian British', comprising 5.5% of the city's total population.

Applications

Across the full pilot, a total of 282 application forms were received, including six from people who applied via the Edinburgh sub-pilot targeting people of south Asian ethnic origin³. 91 application forms were received from people living in Argyll & Bute and 191 were Edinburgh applicants. 58% of the applications were joint applications, which meant that they were from two people applying together. A joint application counted as two individual awards because two individuals were benefiting. The maximum amount any individual could receive was £500 and so the maximum that two people could apply for together was £1,000.

An equalities monitoring form was included with the application form and it was made clear that completion was optional. Of the 282 application forms completed, a total of 247 equalities monitoring forms were returned. A summary of the Equalities Monitoring Report can be seen at Appendix E and the full report is available separately.

³ All overall and Edinburgh-specific figures include those from the sub-pilot.

Awards

After approval by the Awards Panel, Awards amounting to a total of £193,253 were made to 438 individuals. 40% of the Awards were issued to people with dementia and 60% were made to people caring for someone with dementia.

Only 5 applications were unsuccessful, generally because the applicant had either already applied successfully and so was not entitled to a second Award or they were seeking to make a retrospective application (to pay for something bought before the pilot began). Of those who applied jointly, all the Awards except one were given to a person with dementia along with a person caring for them. The one exception was an Award made to two carers jointly.

Across both pilot areas, the average Award per individual was £441, with the average Award issued to people with dementia being £438 and to carers £444. In Edinburgh, the average Award issued to people with dementia was £435 and carers received an average of £442. In Argyll & Bute, both carers and people with dementia received an average Award of £446.

By the conclusion of the pilot, 68% of the total Award monies had been distributed in Edinburgh (including those specifically for people who applied via the sub-pilot targeting people of south Asian ethnic origin) and the other 32% in Argyll & Bute, which was very close to the anticipated distribution of the Award funds. In Edinburgh, people with dementia received 44% of the 302 Awards issued and carers the other 56%. In Argyll & Bute 42% of the 136 Awards went to people with dementia and 58% went to carers.

Devolved delivery model

The direct costs of the devolved delivery model (i.e. delivered by partner organisations on behalf of the Life Changes Trust) was £55,673. Across the whole pilot, it cost an average of £128 to administer each Award. In Edinburgh the average cost of administration was £94 and in Argyll & Bute it was £202.

This difference is unsurprising given the rurality of the Argyll & Bute area and the consequently higher expenses of partner organisations for travel and providing support.

'Administration' included support to the individual throughout the whole process from application to feedback/evaluation as well as partner organisations' attendance at partner planning and review meetings. It also included the cost of processing the applications and issuing cheques or making bank transfers. Therefore, 22% of the total pilot budget was spent on delivery at grass roots level.

In addition, Trust staff supported the pilot and a consultant provided evaluation support.

Section 5: How people heard about the Awards, Eligibility and 'Being Included'

How people heard about the Individual Awards

Most people affected by dementia first heard about the Individual Awards through their local partner organisation, either in conversation at a carers' centre, through their mailing list or because a member of staff in a partner organisation had contacted them specifically about the opportunity. The latter was common where a member of staff was aware of a person who could potentially be helped through the Award.

Other information sources and referral routes were through local dementia teams, information distributed at an organised lunch or a conversation with someone from the Council about other financial matters.

Comments were made by carers about the connection with partner organisations being a positive outcome itself, and partner organisations reported increased engagement and reaching new service users through people coming to them about the Awards. Often involvement continued beyond the discussion about the Awards.

Eligibility

Many Awardees said they felt disbelief and surprise on first hearing about the Awards. One carer said: **"When this was first brought to my attention I thought it was all too good to be true. But there you go...Sometimes good things just do happen to normal people..."** (Carer, Edinburgh).

The elements of the Individual Awards that people found surprising were the simplicity of the eligibility criteria for applying and the level of choice and control over the award, with the broad choice of spending options seen as something quite novel. Indeed, the concept of such person-centred funding was so unfamiliar that for some people it gave rise to initial scepticism and even suspicion. One partner organisation suggested that this may have led to some eligible people not applying for an Award.

These initial doubts were generally overcome through the reassurance of partner organisations, who were able to explain the source of the funding, confirm the authenticity of the Pilot and, where necessary, encourage people to apply. Many Awardees indicated that this was one of the reasons why it had been important for them that the Awards had been promoted through a trusted local organisation.

Some carers also expressed surprise at being included in the Pilot and that their needs were being recognised on a par with those of the person with dementia.

The written feedback provided to the Trust came only from those who applied, received an Award and provided feedback. However, feedback from one partner organisation suggested that where people heard about the Award and decided not to apply, this was most commonly because they believed that someone else would have more need of it than them rather than doubts about the Pilot itself.

Applicants' enormous delight at the simplicity of the eligibility criteria was because this made the application process easy and avoided the need for probing questions. Although only thirteen people of minority ethnic origin received funding, this aspect of the Awards was regarded by MECOPP as particularly helpful in terms of reaching minority ethnic people affected by dementia, some of whom may be particularly hesitant to seek or disclose a diagnosis due to stigma around dementia, or to discuss money matters.

Feelings about being included in the pilot

Feedback from Awardees showed that inclusion in the pilot scheme had positive effects, in terms of feeling valued and supported, even before the benefits of the goods or services purchased with the Award were taken into account.

“This has been a very difficult year and it made such a difference to know some one cared enough to help us to apply for the grant and to give us one.” (Female carer, Edinburgh).

“Many, many thanks for including me in this pilot scheme. Never in my life has anyone offered me money to spend and improve [my] standard of living.” (Female carer, Argyll & Bute).

“It does make you feel better that somebody cares... Because somebody else is... it’s like you’re helping, you know what I mean, without being asked, really.” (Male carer, Edinburgh).

“Someone appreciates what I am doing.” (Female carer, Edinburgh).

Section 6: Deciding What to Spend the Money On

As will be seen in the following sections, there was considerable diversity in terms of what the Award was spent on. This diversity was also commented on in the focus groups, where participants were interested and enthusiastic about the variety of ways in which they had made use of the Award, depending on their own situation. Most awardees expressed approval for the openness and flexibility of the scheme because they recognised how different peoples' needs can be.

"It strikes me that it's probably absolutely essential, that, if you're going to target people and try to make a difference for them, you know, you have to be willing to sort of recognise that that could be quite different from person to person." (Female carer, Argyll & Bute).

"I think for anything to have any value it's got to have a certain personal element to it. Everybody's situation is so different." (Female carer, Edinburgh).

Cultural beliefs and social norms, or previous experience with other sources of financial support, seemed to influence people's expectations of what it would be appropriate or acceptable to apply for, with people reporting initial doubts that they would really be given an Award for their proposed purpose - even when the expected benefits were obvious.

One carer talked about it being wonderful to be trusted to 'admit' to what you needed and said she appreciated that there were **"no questions asked but you'd been trusted. That was nice... You were being trusted."** (Female carer, Argyll & Bute).

Others spoke about how, when you are affected by dementia, it is easy to live in an **"enclosed little world"**, a **"little box"**, and are just **"embroiled"** in the business of day to day living. They described how the opportunity of the Individual Awards helped **"to sort of open your mind up a little bit"** (Carers, Edinburgh).

People felt that the flexibility of the Trust's Award scheme allowed for creative thinking and that this was a good thing in terms of maximising benefits. One focus group, when asked what they would say to someone thinking about applying for an Individual Award, advised that they should:

"... think laterally if you can."

"And vertically."

"And diagonally!"

(Carers, focus group, Edinburgh).

It was also appreciated that this type of flexible financial support could help to improve the quality of life of people of any age and at any stage of dementia. This was reflected in the findings, with uses for people with dementia varying from a health club membership for swimming to a high dependency chair for a woman with advanced dementia living in a care home.

Partner organisations generally also agreed that this wide choice of spending was very positive, because it helped people to maximise benefits depending on individual circumstances and also because of the enormous value of the thought-provoking process of deciding whether to apply and what to apply for. It was also felt that the application process created an opportunity for helpful, constructive and open conversations.

Some applicants already had something specific in mind which was the obvious priority for them, but for many this was not the case. Often people had a whole range of challenges and unmet needs which could be addressed through the funding. However, these were not immediately brought up by potential applicants, who revealed that they had always 'just got by', sometimes in situations of extreme adversity. Awardees pointed out that careful thought about how best to use the money was an important part of the process and that more time should be allowed for this, to avoid rushed or less effective decisions.

"Because it was unexpected, you did have to have time to think - not only what you wanted but why you wanted it, if that makes sense"

(Female carer, Argyll & Bute).

This carer pointed out that it could also involve some 'to-ing and fro-ing' - in her case, discussing things with the support worker at the carers' centre but then going back to talk it through with her partner, who has dementia, so that he was also included and involved in the process of thinking about what they wanted and how they thought it would help.

Various strategies were used during this important stage and different people were involved. Some reported talking things through with their paid carers, as they would probably be able to suggest possible uses of the Award. One Awardee pointed out that their paid carers come in twice a day and are just part of the family now. In many cases, other family members were involved in discussion. One carer described how she and all her siblings got together and talked it through, making a list of things that would improve the quality of life of their mother and then carefully prioritising them.

Many people talked through their options with a member of their local partner organisation, some of whom adopted solution-focused techniques to structure a conversation which would help people to explore their own priorities and ideas to improve quality of life.

What was clear from the feedback was that many people saw the Award as a 'golden opportunity' and were determined to make the most of it.

Section 7: The Application Process

Simplicity seemed to be key for people already navigating a complicated world and the relatively straightforward application process was appreciated by those who provided feedback in focus groups or interviews. Reference was also made to the positive way the Individual Awards were presented, in a world where there can be stigma around applying for financial support. The help of the partner organisations in completing the application was widely mentioned and generic feedback from the Partners was that the majority of applicants preferred to have support to fill in the form. The layout of the form had been designed to be dementia friendly, with a large font size and plenty of spacing. This made it bulky, which may have looked intimidating to some applicants at first glance.

Applicants were also requested to fill in an equalities monitoring form to evaluate the reach of the Pilot, in particular to people with 'protected characteristics', but this was not compulsory. Partners found that it could be uncomfortable asking elderly applicants about their sexual orientation for this purpose.

On the whole, the feedback from Awardees suggested that it was important to them that the opportunity had come through a trusted organisation. Also, that some people appreciated gentle reminders to encourage them to submit the application and that many people had needed some encouragement to apply, thinking that perhaps it was not really intended for people like them, or that someone else might need it more. It was also pointed out that the option to fill in the application at home and send it in was important for people who might have difficulty getting to a partner organisation's premises.

Some psychological benefit seems to have been enjoyed even before the money was spent, as a number of people spoke of the pleasure of having something to look forward to. At the time of providing feedback, one Awardee had not yet had the opportunity to get away for their planned break, but stated that **"looking forward to it will help"**.

Two sisters who had multiple caring roles savoured the anticipation of their short break away: **“And every time we sat down and talked about it we got more excited. I think there was a bit of dancing and, you know, screaming involved too! [laughing]”** (Female carers, Argyll & Bute).

Likewise people looked forward to complementary therapy sessions, trips to the hairdresser or learning new skills with the I.T. equipment they were buying.

At the spending stage, many individuals or families made their purchases on their own. However, the staff of partner organisations felt that it was part of their role to provide support if required at this stage, even though such involvement had not been anticipated. In some cases they provided considerable support at the spending stage, illustrating the case-by-case flexibility that working through local partner organisations can provide.

Spending the Award was more straightforward for some people than for others and the timescale necessary often depended on an Awardee’s resources (including time, transport, access to the Internet, mobility and confidence). It also varied depending on what the Award was being spent on. Buying one easily available item involved some research to get the best deal but was then simple, while arranging for work to be done on the house or garden could be complex and depend on the work schedule of suppliers or tradespeople. In some cases, it was necessary to negotiate or to come up with arrangements for pre-payment of services to then be enjoyed over a period of many months. In addition, some jobs may be best carried out at certain times of the year (garden projects, replacing a heating system, roof repairs) or it may be difficult to arrange pre-payment, leading to a longer spending period for ongoing services.

Finally, life with dementia is unpredictable and circumstances can call for adjustments on a case-by-case basis. It was appreciated that a timescale for spending was necessary for practical reasons and also to provide an impetus to make it happen. However, the very widely-held view among both Awardees and partner organisations was that the time allowed for spending should be longer than the two months piloted and should also be as flexible as possible where circumstances require this.

A feedback report from partner organisations provides other useful information on the administration and support processes for the pilot – what worked well and what could be improved – and will help the Trust develop future plans.

Section 8: Spending the Award

The pleasure of choosing

For some Awardees, in addition to the benefit of the goods or service acquired, the actual spending of the Award became a hugely pleasurable part of the Individual Award experience. Having choice seemed to be central to this, an indication of the added benefits of financial empowerment as opposed to provision of standard items. One woman with dementia who had lost a lot of weight had thoroughly enjoyed a shopping trip with her daughter to buy some new clothes, while another had loved the excitement of choosing new items for the house. For a man with dementia, buying a new supportive chair had held a real sense of occasion.

What the Awards were spent on

From the descriptions of how the Awards were used, the Trust identified categories of spending to provide a helpful overview. A number of issues should be borne in mind in interpreting the analysis of spending:

- the feedback on spending was qualitative and the amount of detailed breakdown provided varied from person to person
- some categories involve a small number of cases. Reported percentages are intended only to provide an impression of the sort of things that people used the money for
- people's choice of spending may have been influenced by many factors, including inspiration from others around them, local resources which could be tapped into, the time of year and the timescale of the Pilot

The breakdown provided here serves mainly to highlight:

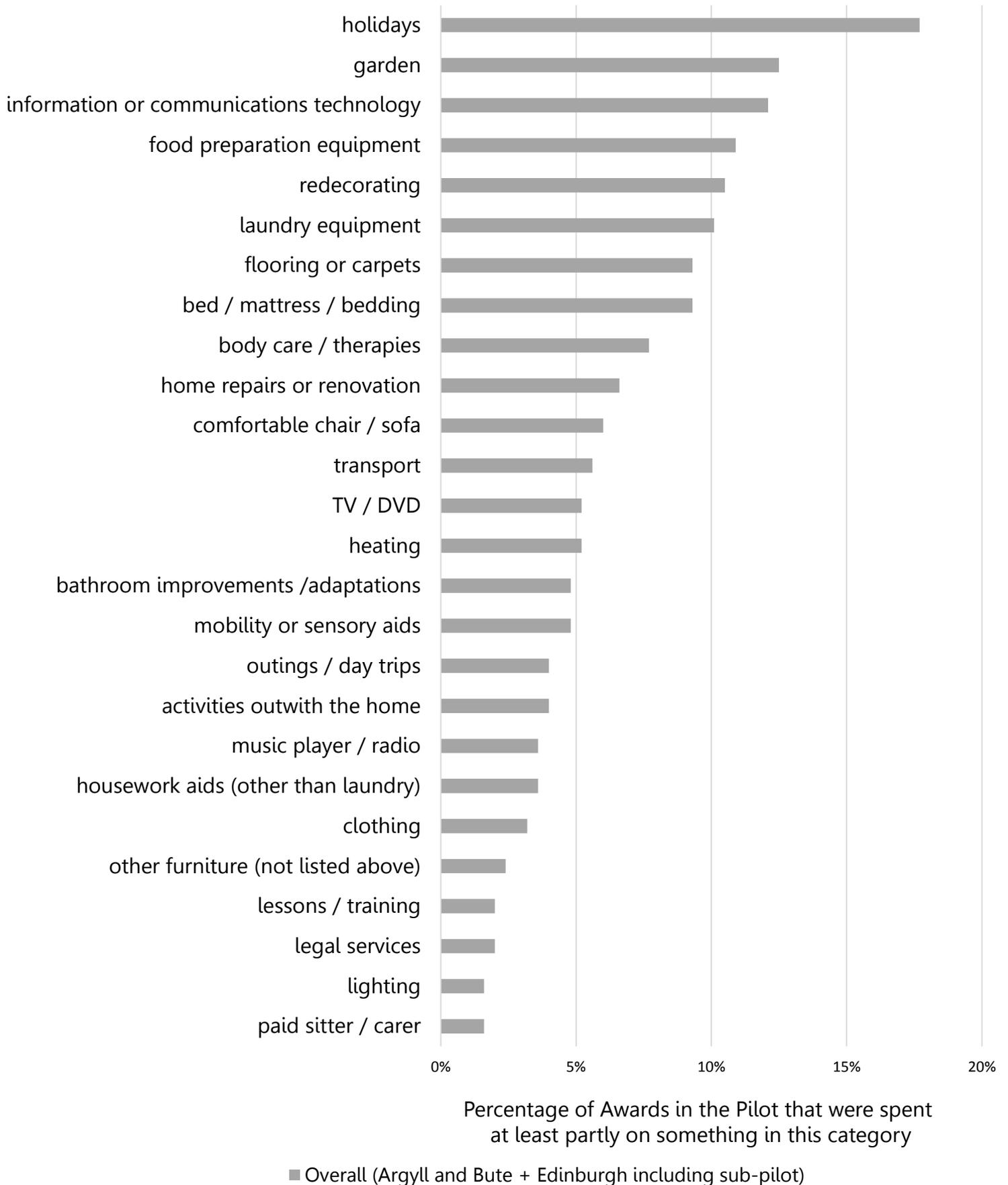
- (1) any areas of spending priority which might be focused on in other initiatives
- (2) the diversity of spending
- (3) any unusual or striking uses of the Award which might spark ideas

Bar Chart 1 shows each category of spending by the percentage of Awards in the Pilot for which at least part of the Award was spent on something in that category.⁴

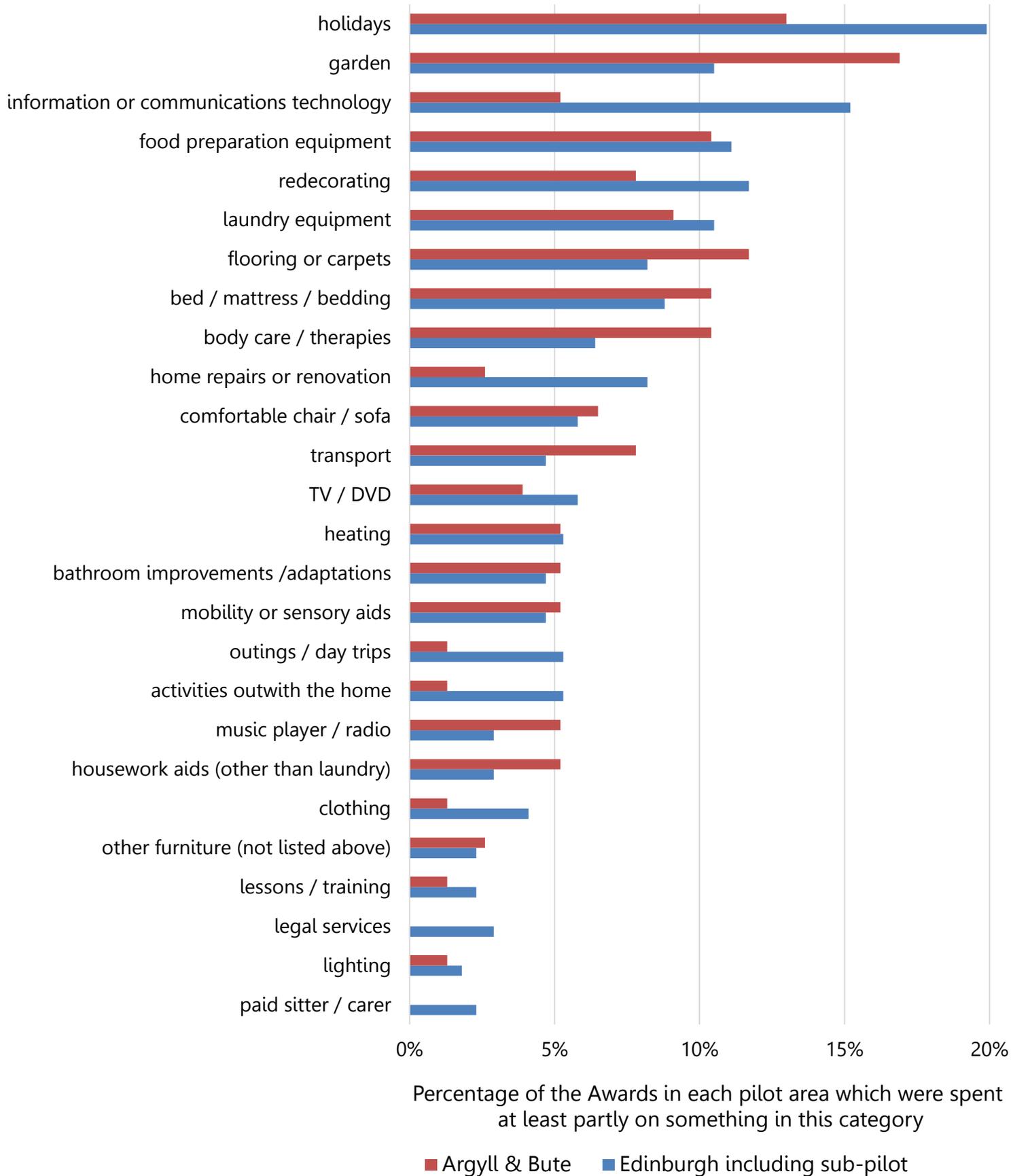
Bar Chart 2 shows the same information broken down into the two pilot areas of Argyll & Bute and Edinburgh.

⁴ As some Awards were used for more than one thing the percentages do not add up to 100.

Bar Chart 1: Breakdown of spending in the Individual Awards Pilot



Bar Chart 2: Breakdown of spending in the two pilot areas



It can be seen that holidays (including short breaks), garden work and information or communications technology were popular uses of the Award, as were home repairs or improvement jobs, food preparation equipment or laundry equipment. A notable finding was the large percentage of the Awards which involved the services of gardeners or other tradespeople. Table 1 below shows the prevalence of this type of spending.

Table 1: The categories of spending of the Individual Awards in this Pilot which potentially involved the services of gardeners or other tradespeople.

Category of spending	% of Awards in each area spent at least partly on this category		
	Edinburgh	Argyll & Bute	Overall
garden	10.5%	16.9%	12.5%
redecorating	11.7%	7.8%	10.5%
flooring or carpets	8.2%	11.7%	9.3%
home repairs or renovation	8.2%	2.6%	6.6%
heating	5.3%	5.2%	5.2%
bathroom improvements or adaptations	4.7%	5.2%	4.8%

Feedback was received in relation to four of the six Awards issued by MECOPP. Given the small numbers, this is not presented separately in the breakdown of spending, but is included under 'Edinburgh'. A cultural issue reflected in the MECOPP feedback was the enormous value of the internet and satellite TV for accessing films and other viewing to meet the cultural, linguistic and religious needs of ethnic minority people. In one case, installing satellite TV in a care home reduced social isolation in this way and led to a man with dementia engaging more in conversation, as he talked about the programmes he had watched. In addition, as for many people in the Pilot as a whole, the internet enabled quality communication with family and friends living a long way away.

Feedback from partners and people receiving the awards in Argyll & Bute indicates that they can experience a range of challenges including:

- reduced availability or choice of tradespeople to carry out work
- reduced choice of items / services
- higher cost of many items or services, including higher delivery charges
- potentially, a distance to travel to access the internet (if there is no internet at home) to research products and also to go shopping

From Bar Chart 2 on page 28, it can be seen that there were differences in spending between the two pilot areas.

A higher percentage of the Awards in Argyll & Bute were spent at least partly on:

- the garden
- replacing flooring or carpets
- body care or therapies
- transport
- music player / radio
- housework aids (other than laundry equipment)

A higher percentage of the Awards in Edinburgh were spent at least partly on:

- holidays
- information or communications technology
- redecorating
- home repairs or renovation
- outings or day trips
- activities outwith the home
- clothing
- legal services
- paid sitter or carer

The most striking contrast (and involving enough cases to consider it a genuine difference) was in the category of I.C.T. It would be interesting to investigate whether this is due to local demographics, infrastructure (such as the availability of good internet access in urban and rural areas) or different priorities in the two areas.

Geographical issues became clearer through reading the Awardees' feedback. People in Argyll & Bute who had used the Award for vehicle-related costs (repairs, MOT, insurance or a deposit towards replacing an old vehicle) stated the fundamental importance of their car, which was described as **'a lifeline for us'** and **'essential'**.

One carer describing their situation wrote **"I hope this explains how important and precious a reliable car is to us"** (Carer, Argyll & Bute). In both pilot areas, Awards were used to pay for taxis to visit a loved one in a hospital or care home. In rural areas, however, the distance could be considerable and the cost greater.

Cultural events (theatre, cinema, concert) or gym memberships were purchased by a number of the people receiving Awards in Edinburgh, but did not feature in Argyll & Bute where feedback about physical activity described golf or walking with the dogs. On the other hand, spa treatments were popular in one area of Argyll & Bute, sometimes as a new experience, suggesting people recognise that there are local resources for self-care and use these if given the opportunity.

A few areas of spending are looked at a little more closely below, to give a sense of the very personal nature of people's choices.

Holidays or breaks and "making memories"

This was an extremely popular use of the Award and something to look forward to. Holidays often involved visiting family, seeing friends or going back to familiar places, which could aid reminiscence. For couples or families there was sometimes a sense in the feedback of cherishing those things that had shared meaning for them, nourishing relationships.

The Award helped one couple to celebrate their silver wedding anniversary, while in another case a carer was able to take her husband and teenage children on a short break to thank them for their support which has enabled her to continue caring.

Many feedback letters referred to 'making memories' as part of their reason for using the Award in this way, including creating an opportunity for a grandparent with dementia to spend special time with the grandchildren, creating memories for them too.

One woman had been desperately in need of a break from her caring role and wrote about how this Award had averted a crisis, restoring her stamina and resilience. For some, a holiday also created an opportunity to review the care needs of the person with dementia or to reflect on a situation and engage in joint problem-solving.

From seeking adventure to relishing the most uncomplicated and relaxing break possible, holidays were life-affirming times. As one woman said of a holiday with her mother, who has dementia, and other family members: **"We came back refreshed and relaxed with a positive outlook and new memories to cherish"** (Carer, Edinburgh).

The joy of the garden

Garden maintenance or improvement was another very popular use of the Award and, along with the aesthetic appreciation of the end results, it often lifted worry and brought a sense of getting things under control. Improved natural light levels in the home were a benefit appreciated after pruning and clearing plants which gave back to one couple their view of the loch. A different approach was taken by others where some turfing and the purchase of adequate tools allowed them to continue to enjoy gardening themselves.

One Awardee did not have a garden but anticipated the enormous pleasure her flowering window boxes would bring. In one case, a carer used to tend her allotment but worried about hurrying off to visit their mother. The Award was used to buy a shed and this person now takes their mother to the allotment three or four times a week so they can enjoy it together.

As well as the joy of a beautiful outdoor space, for some there was the fun and satisfaction of a creative project, increased physical well-being from getting out into the garden and more connection with the outside world, from being able to talk to the neighbours again or being able to 'watch the world go by'.

Information Technology and being connected

"The gift that keeps giving." (Female carer, Edinburgh)

The purchase of I.C.T. equipment (predominantly laptops and tablets) was an extremely popular use of the Award and was appreciated for its very many purposes, including:

- reducing a feeling of confinement by connecting to the 'outside world'
- writing, when handwriting has become difficult
- easier management of finances through home banking
- online shopping and ordering goods
- access to culturally and linguistically diverse material
- keeping up old skills and maintaining identity
- the excitement of learning new skills
- ready access to information and advice
- access to photos in digital form, aiding reminiscence
- access to music and lyrics
- escapism
- watching TV programmes or films (including close up with subtitles)
- studying and research for a carer's personal development and future career
- sharing a communal calendar to coordinate family commitments
- making a hobby compatible with a caring role
- to have a shared interest
- staying connected with family and friends

The latter was especially important for those with family members and friends at a distance, and using video call systems for communication with grandchildren was **"phenomenally fun"** (Female carer, Edinburgh).

One carer felt they needed to access information to help with their caring role and also had family abroad whom they wanted to keep in touch with more frequently: **“I felt isolated and unsure about how to cope with future demands.... (now) I can communicate more easily, so my life / confidence have improved”** (Carer, Edinburgh).

People expressed a sense of empowerment at being able to access information about medication and side effects, giving a feeling of increased control over health-related issues.

The striking thing about I.T. equipment was its versatility, since it could be used by various people in a household in different ways and its use could change in line with circumstances. A communal calendar had proved ‘indispensable’ to one family for co-ordinating appointments.

Other communication devices purchased were a big button mobile phone, described as **“the best piece of equipment my mother has”** (Carer, Edinburgh), an intercom between bedrooms and a nuisance call blocker.

The home

In many cases, spending on the home improved safety by reducing the risk of falls. Often it increased mobility and independence or improved hygiene. In one case where double incontinence meant that the bedroom carpets had become very difficult to clean, the carpets were removed and new flooring fitted:

“The fact that I don’t have to be on my knees scrubbing the carpet every other day, that’s... that is so... Oh!!” (Female carer, Argyll & Bute)

“...to have that flooring down is just... like heaven on earth... you know. It’s just lovely.” (Female carer, Argyll & Bute)

Adaptations to bathrooms, such as payments towards a wet room or installation of a walk-in shower and stool, could be life changing for the person with dementia in terms of renewed confidence, dignity, ease of hygiene and maintaining independence.

In some cases it really allayed worries people had about the sustainability of independent living:

“The shower and stool has enabled my husband his independence where, without this addition, we had been contemplating whether we could cope at all... now we can!” (Female carer, Argyll & Bute).

In another case, renewing the bedroom floor made it suitable for the hoist which had become necessary for the care needs of a man with dementia. This enabled him to stay at home to be looked after. On a financial level, the cost of the flooring could be considered in relation to the cost of residential care. On a personal level, if that person wished to remain in the family home it may just have been priceless.

Awardees conveyed through their feedback just how important a pleasant and functional home environment was as they, or the person they cared for, spent the vast majority of their time within the house.

Redecorating gave a huge boost, lifted mood and renewed people’s pride in their home. Importantly, there was a sense of ownership of these creative projects: **“I can’t thank you enough for giving me the opportunity to make my home look better”** (Female carer, Argyll & Bute). This carer talked about how the Award had motivated her to continue making changes, gradually redecorating the rest of the house one room at a time. A woman with dementia living in a care home described how the Award had enabled her to buy things to brighten up her room, which cheered her up and made her feel more at home.

A further flavour of the nature and diversity of spending of the Individual Awards in the Pilot can be found in the next section, which focuses on some key outcomes.

Section 9: Outcomes

The Awardees' feedback illustrated how one improvement, enabled by the Individual Award, could lead to many positive outcomes and how some important outcomes could be achieved in many different ways. Peace of mind, connection, empowerment and health and well-being were common outcomes reported in feedback.

Peace of mind

Peace of mind supports mental well-being by providing comfort, reassurance and satisfaction. Individual Awards gave peace of mind in many different ways.

For example, legal services were paid for to set up wills and powers of attorney. Where this issue had been on someone's mind for a long time, the Award provided the funding, the impetus to get it done and satisfaction that something important had been achieved.

Many other activities supported by Individual Awards improved safety and brought peace of mind. For example: replaced flooring for fall prevention; repairs to a fireplace; rewiring; improved lighting; the installation of an induction cooker; a keysafe system for the home help; renewed security fencing for the garden; replacing an old, sub-standard oil tank for the central heating; car repairs; adaptations to enable safe bathing or showering; tree surgery; Likewise, replacing very old appliances (such as cookers, heaters and boilers) removed worry about anticipated breakdowns and replacement parts no longer being available.

A service and maintenance contract for a stairlift brought peace of mind to one couple who had been dreading a breakdown. Awards were used to pay for M.O.T.s and car insurance. A warmer home due to improved heating or heat retention meant carers were no longer worried about the person with dementia feeling cold. Other things which brought peace of mind were: roof repairs; a nuisance call blocker; an intercom between bedrooms; a communal digital calendar; prepayment of utility bills; respite care for a person with dementia; being able to order prescriptions online; access to internet banking to control finances; having access to advice and information online when needed; and a big button mobile phone.

Connection

Feeling connected to others and the world is important for mental well-being and reduces isolation and loneliness. The Individual Awards strengthened people's 'connectivity' in many ways. Connection with family and friends was increased through access to Internet communication; outings, trips or holidays together; transport for visiting a relative in hospital or care home; regular shared activities (such as going to the cinema or to a health club); but also through family having more quality time together due to household tasks being made more manageable through housework aids and appliances. People's connection with their past was strengthened through digital photos, holidays, revisiting familiar places and through music. Renewed connection with nature was enjoyed by those who could once again spend more time outdoors due to gardening work or whose view from the window had been restored by clearing of the garden, with the pleasure of watching the cats and the birds again.

Connection with the outside world through TV, radio and internet was particularly important to those who spent most of their time in the home. Connection with the community was helped by being able to get out and about again thanks to mobility aids, vehicle running costs or transport, through being able to be out in the garden again to chat with the neighbours, and through regular activities outside the home such as a weekly choir, having a football season ticket, cinema pass, golf or health club membership, or regular appointments at the hairdressers (which was about much more than a haircut).

Empowerment

Empowerment enables people to have greater choice and control over their lives. Individual Awards empowered people in many ways. Examples of empowerment included access to information and knowledge through the internet; training courses; driving lessons; increased freedom and independence through home adaptations and mobility and sensory aids; a new bicycle or other transport. The purchase of a fridge/freezer was financially empowering, freeing up fridge rental money for the monthly budget.

One woman with dementia who lived in an assisted living flat was put to bed by the carers very early every evening. Installing a TV in her bedroom enabled her to watch later programmes on TV if she wished, giving her back at least some control.

Other empowering improvements supported increased choice - vehicle running costs allowing a person to do their own shopping again, or a tumble dryer, providing a wider choice of clothes to wear each day.

Health and well-being

Individual Awards were also used to directly improve people's physical and mental well-being in a variety of ways. Improving sleep was a great priority and some people used their Award to buy a new bed or set up sleeping spaces in separate rooms. Others used the Award to pay for: physiotherapy or osteopathy treatments; a S.A.D. light to boost mood; bathroom adaptations to improve personal hygiene; better heating or a comfortable chair to increase physical comfort; food preparation equipment (such as a microwave, soup maker, blender or a freezer to stock up on home cooking) to improve nutrition.

Some used the Award to improve physical activity, including paying for a health club or golf club membership, a new bicycle, a golf trolley or waterproofs for walking the dog or cycling. Others reported that they were able to reduce stress by using the Award to pay for regular swimming, holidays, massage, complementary therapies, music and social support. Finally, the Award brought a healthy dose of happiness and delight for many people!

Section 10: The 'Ripple Effect'

The feedback from the Pilot illustrates that improvement in one area of life can lead to:

- 'carryover effects', with the consequences lasting for some time
- 'spillover effects', with the improvement having effects on other areas of life or on other people

These can be thought of as a 'ripple effect'. Three examples of how the ripple effect was described by Awardees are presented below. Feedback also showed that the Award process itself can have a ripple effect and this issue is also explored.

Mobility, freedom and family relationships

One person described with enthusiasm the multiple, positive outcomes of the Award and a ripple effect on his physical, mental and social well-being and on family relationships. This example is presented in Diagram 1, with his purchase of a second-hand mobility scooter through the Award being the 'pebble' which created these ripples.

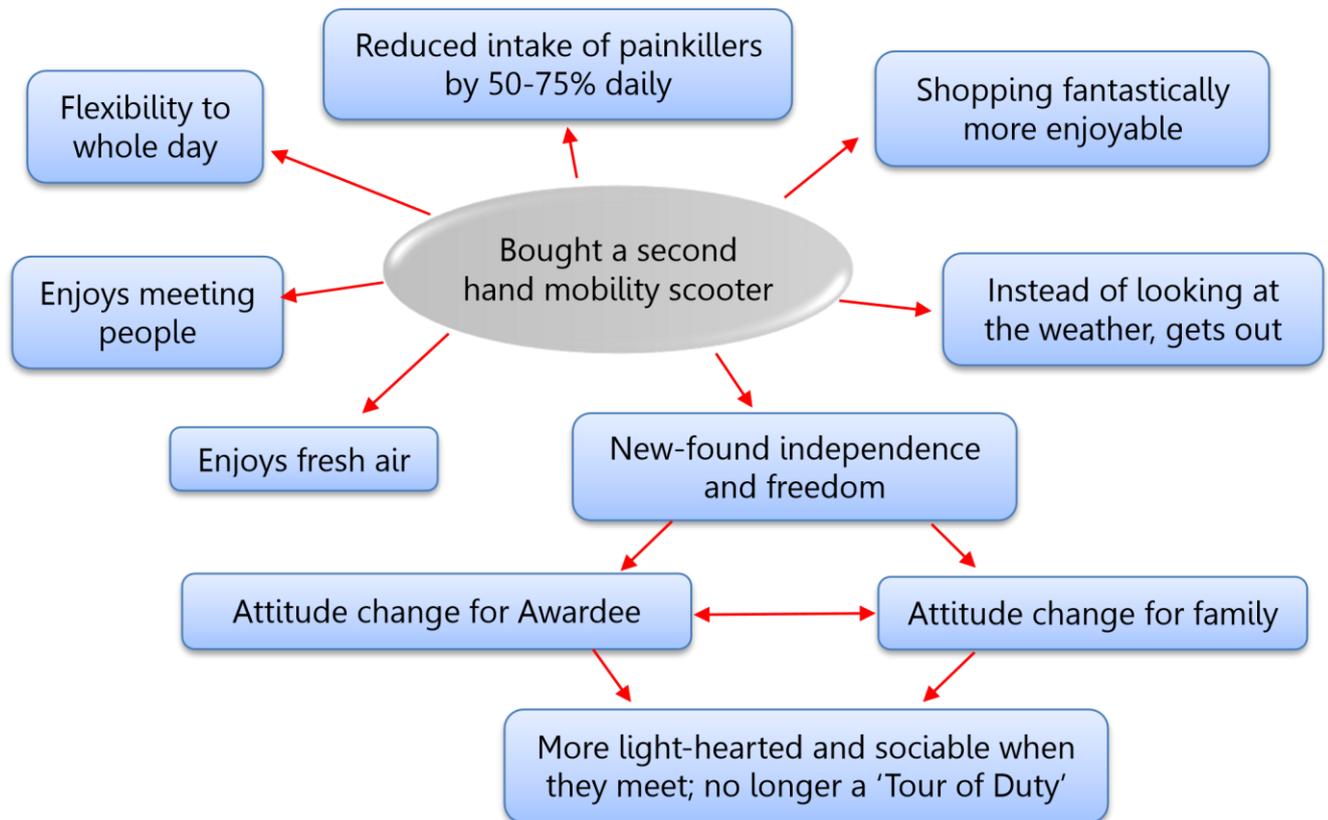


Diagram 1: The immediate outcomes and ripple effect of using the Award to buy a second-hand mobility scooter (as described in this person's feedback letter).

(Male Awardee, Edinburgh).

Involvement and satisfaction

When a man with dementia and his wife used the Award to buy a new garden shed, this had a ripple effect in relation to the laundry, as can be seen in Diagram 2. In addition, the man got involved in painting the shed. He had not used a paintbrush for many years and was very pleased to have done it. The shed had provided **“a reason for getting outside and doing something.”** (Feedback from female carer, Argyll & Bute).

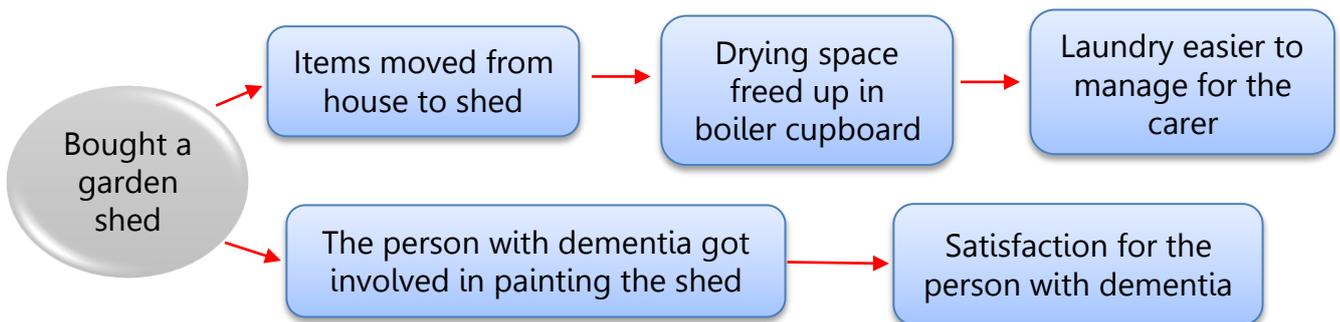


Diagram 2: The ripple effects for a person with dementia and his wife of buying a garden shed.

Feedback from other Awardees shows that facilitating laundry can in turn have ripple effects in terms of freeing up time for other activities or in terms of emotional well-being, with a feeling that things are under control.

It should be noted that the theme of 'laundry' is one of a few connected with issues around continence. Several Awards were spent on items that would help in managing continence needs – a change of bedding, change of clothes, change of shoes, lino instead of carpet, washing machines and tumble driers. Some Awardees commented that the Awards process provided them with an opportunity to talk more openly about the challenges that managing continence needs can pose.

Developing shared interests

One woman with dementia and her husband used the Award to buy a laptop. Their previous employment had involved computers and she was aware of losing her skills. Her husband reported that they were now both going to a computer course at the library, so it has provided a shared interest. This experience gave them the incentive to consider a further shared interest by buying a cinema pass they can use together. This is illustrated in Diagram 3.

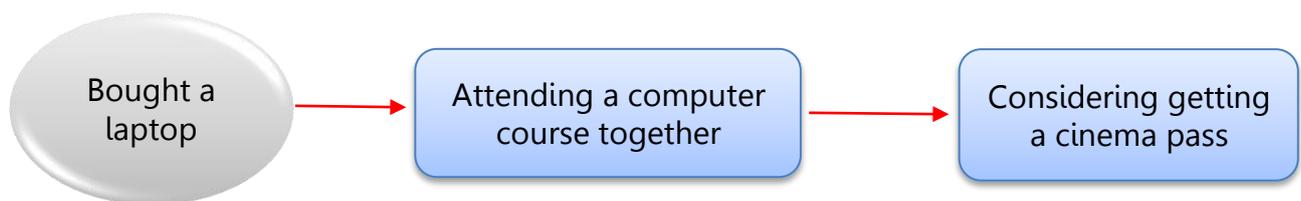


Diagram 3: The ripple effect for a woman with dementia and her husband of the purchase of a laptop through their Award. (Feedback from male carer, Edinburgh.)

Ripple Effects of Award Process

The timescale for feedback from the Individual Awards pilot allowed for immediate and medium term ripple effects to be reported directly. In many cases sustained, long term benefits can easily be inferred, such as in the case of structural changes to the home to facilitate activities of daily living. However, the feedback also revealed aspects of participation in the Individual Awards pilot which, in perhaps a less obvious way, may contribute to lasting changes in the lives of the Awardees. These included three notable factors.

The first was the **awareness-raising effect of the Award**. People affected by dementia were encouraged to think quite strategically about possible ways of improving their quality of life. In addition, through the Awards, others - notably family members - sometimes saw ways in which they might be able to provide useful support. Examples of this included helping with the future maintenance of a garden or providing respite care to allow the principal carer to have a break.

In addition, the opportunity of the Awards sparked very open conversations with members of the partner organisations, and sometimes with peers, which led to a greater awareness of people's situations and the effect of dementia on their family life.

The second was that for some people, the Awards pilot **brought them into contact with a support organisation, strengthened that connection or led to increased engagement**. Given the comments in the feedback from many Awardees about the importance of these organisations to them, it is safe to say that for some people affected by dementia this can be life-changing.

The third factor was the reported **motivational effect of the Individual Award**. A great number of Awardees spontaneously commented on this in the feedback, using terms such as 'motivation', 'incentive', 'push', 'boost', 'impetus' or 'getting the ball rolling'. One Awardee, having successfully managed the Award process and got satisfaction from seeing the positive effect on their family, described the psychological effect of this:

"I feel, having done this, and the enjoyment it brought to those around me [...] and the fact that I had the motivation to organise something has encouraged me to look at what else I could try and achieve next year." (Awardee, Edinburgh).

This shows that the long term benefits of a financial award of this nature comes from both the direct improvement to life enabled by the financial support, and also the boost the process given to peoples' confidence, motivation and self-efficacy.

Section 11: Other Significant Findings

The evaluation identified three wider issues for people affected by dementia in Scotland.

Poverty

Feedback indicates that there are people living with dementia in Scotland who are in poverty. There are also carers striving to provide the best possible care with extremely limited resources. There were people who did not own a bed or who were dealing with incontinence without an automatic washing machine or without a change of bedding or shoes. There were people who could not have afforded to set up the necessary power of attorney without the Individual Award.

Some people described giving up a career to be a full-time carer and the difficulties of living on state benefits or on a pension, with the stress of having to watch every penny and worrying about how to pay for the additional costs associated with looking after someone with dementia. Others talked about the unexpected costs of dementia. Some people who had always 'just got by' are now living in situations of extreme financial adversity.

One full-time carer whose mother had just gone into residential care described going to claim Job Seeker's Allowance for the first time as a humiliating and embarrassing experience.

Time-limited support

Some carers of people with dementia raised the problem of time-limited support. People appreciated the one year of post-diagnostic support provided in Scotland, but even those who were still enjoying visits from a link worker were anticipating with some dread the moment when that support would end. There was a fear of being "**cast to the winds**" (Male carer, Edinburgh) and "**basically left to try and... hang on**" (Male carer, Edinburgh). They would like more continuous support to be available.

Lack of emphasis on exercise

At one feedback focus group, the lack of emphasis in Scotland on exercise for people with dementia and their carers was raised. It was suggested that every block of retirement flats should have a gym or some dedicated space to encourage regular exercise, and that more attention should be given to the importance of exercise for people affected by dementia.

Section 12: The Experience of the Delivery Partners

The Partners staff and volunteers provided feedback about the Individual Awards Pilot from their perspective. They were happy to have participated in the Pilot, feeling that it had brought real benefits to the Awardees.

Some commented on how lucky they were to see the impact of the Individual Awards and the joy they can bring. They were enthusiastic about the personalised nature of the funding and the open choice of spending, being very aware of people's diverse needs and priorities, and felt that it was very important to keep the application process as easy and streamlined as possible for the applicants. They reported that potential applicants were almost invariably concerned initially about whether there was someone else who needed the Award more than them.

The Award Panel system had worked well, not only in ensuring transparency and rigour in the awarding process but also because it created another opportunity for contact between organisations, sharing ideas, information and local knowledge and also creating an opportunity for challenge and reassurance.

The Awards had helped to bring new service users into some organisations and had created 'head space' for people affected by dementia to stop and think about possibilities for change. The opportunity had led to open conversations, through which needs and solutions were explored.

The Partners supported very many of the applicants with completing the forms, including filling in guided feedback letters over the phone. They emphasised the importance of their role in supporting people right through the process if required.

They also observed that sometimes an Award might seem to have had an effect for a limited time due to the awardee's circumstances changing, but the benefit could still be enormous and life-changing. Partners felt that the impact of Awards should not be gauged only in terms of the duration.

The relatively short timescale of the Pilot was challenging and the general feeling was that the administration process could be more streamlined to optimise efficiency and facilitate flexibility for the Awardees.

A full report of the feedback from the partner organisations will be presented to the Life Changes Trust to inform decisions about how to manage any future Individual Awards Schemes.

The 'feel-good factor' for Partners was significant, with the Argyll & Bute Partners saying they felt like the CalMac fairies!

Section 13: Conclusion and Next Steps

There can be no doubt that the Awards made to date have created better lives for the vast majority of the 438 individuals who received them and that wider benefit has been achieved.

The evaluation findings raise a number of issues that need to be reflected upon and to inform the approach that the Trust takes with any future work of this nature. For example:

- The Awards, and the process, were person-centred, enabling people to choose what would be best for them. This approach was empowering and supported – it should be fundamental to future schemes.
- The Awards process was supportive, with necessary help provided by staff and volunteers of trusted, local organisations. This approach is more costly and time intensive but brings many benefits. How can this approach be replicated elsewhere cost-effectively?
- The Award was given as a gift - the Trust deliberately chose to call it an 'Award' as this term was felt to be more positive than 'grant'. The partner organisations were able to present the Awards in this spirit which perhaps gave the Awards greater meaning to individuals. It was very important that the Award was administered by local and trusted organisations who could provide local, flexible support and allay fears and suspicions.
- Simplicity is essential and the partner organisations felt that the scheme could benefit from even greater streamlining.
- People living with dementia and their carers know what they need when given the 'head space', freedom to choose and support to think things through, which is one of the principles behind person-centred and self-directed support.
- People can be trusted with money - another principle behind person-centred and self-directed support.

- Relationships were vitally important in making these Awards work. The Awards, in turn, helped create or restore a number of relationships which led or will lead to further benefits.
- A number of the needs met by the Awards could (and in some cases, should) have been met by the local authority, the NHS or another public or voluntary fund. There will be a variety of reasons as to why this is not happening in Argyll & Bute and Edinburgh (and probably other parts of Scotland). We need to better understand why families affected by dementia in Scotland might be living without essential items such as beds, bedding, a change of clothes or adequate support to meet continence needs at home, and work with others to improve the situation.
- What are cost-effective support and administration arrangements for Awards of this kind? The cost of delivering this pilot was 22% of the total budget, but the process was effective – would lower overhead costs reduce effectiveness?
- A good proportion of the costs were due to ‘home visits’ by partners. These visits were considered by a number of joint applicants as being crucial to being able to make decisions with the person living with dementia. This could be considered an equalities issue if the lack of a home visit would mean that the person with dementia could not participate fully in the Awards process.
- The pilot scheme gave people 2 months to spend the Award. Most felt that this was too short.
- There is an opportunity to improve wider community involvement in helping to meet the needs of families affected by dementia. This may be through dementia friendly communities, or part of generic community development in an area. Often needs are not met because people who could provide support and those who need it are not connected.

- The outcomes of 'peace of mind', 'connection' and 'empowerment' are useful indicators of 'well-being'. These and similar outcomes can help us develop a clearer definition and measures of well-being for people affected by dementia.

These are just some of the many considerations that will be discussed by Life Changes Trust staff, Trustees and advisors to inform decisions about our future work and investment on Individual Awards and complementary areas.

APPENDIX A – Application Form

The application forms were adapted in each area by the delivery partners to include their name and logo as well as that of the Life Changes Trust and Big Lottery Fund Scotland.

People Affected by Dementia

Individual Awards – Application Form

The Life Changes Trust is offering small amounts of money to people affected by dementia living in **Edinburgh / Argyll and Bute** (insert area specific to partner agency) to:

- spend on something that they think will make their life better
- enable them to do something that matters to them which, without this Award, they would not be able to do

You can apply for any amount up to £500 per person.

The Life Changes Trust is delivering these Individual Awards locally in partnership with (partner agency).

Please read the guidance notes before filling in the form.

1. Your personal details

First name

Last name

Important – to be able to apply, you need to live in **Edinburgh / Argyll and Bute** (insert area specific to partner agency).

Address

.....

.....

Postcode

How are you affected by dementia?

• I have dementia

OR

• I care for someone with dementia for more than four hours a week and don't get paid for it

2. JOINT application

Two people can apply for an Award together if they wish, for example, a person with dementia and the unpaid person who cares for them.

Is this a joint application Yes No

If YES, who is applying with you? Please give their name and details.

First name

Last name

Important – to be able to apply with you, they also need to live in **Edinburgh / Argyll and Bute** (insert area specific to partner agency).

Address

.....
.....
.....

Postcode

How are they affected by dementia?

- They have dementia

or

- They care for someone with dementia for more than four hours a week and don't get paid for it

3. Applying on behalf of someone who lacks capacity to do it themselves

If you are applying for an Award on behalf of a person who lacks mental capacity to do so on their own behalf, you must provide evidence that you have Power of Attorney for their financial affairs.

Are you applying on behalf of someone who lacks capacity?

Yes (you will be asked to provide evidence to (partner agency))

No

4. Your request

How much?

I am/we are applying for £

What for?

I/we would use the money to

.....

.....

.....

.....

.....

How will this make a difference to your life?

This will make a difference to my/our life because

.....

.....

.....

.....

.....

.....

I/we would not be able to do this without this Award

Yes

No

5. Your application result

How can we get in touch with you?

I want to be contacted by:

- Home phone
- Mobile phone
- Email

My phone number is

My email is

If successful, how would you like the money to be paid?

Please pay it:

- into my bank account

or

- by cheque

If you would like the money paid into your bank account, you will be asked to provide bank account details.

6 Declaration

- The information I have put on this form is correct at the time of writing.
- I understand that (partner agency) may ask for some more information to help them make a decision about my application.
- I agree that (partner agency) can share the information I have given with the Life Changes Trust.
- I understand that (partner agency) and the Life Changes Trust will follow Data Protection law and will not share personal information with anyone else without my permission.
- If successful, I/we understand that I/we will need to sign a letter of award to accept the grant.
- I agree to give receipts to (partner agency) to show that I have spent the money as agreed.
- I agree to give feedback about how the money has made a difference. This is to help the Life Changes Trust understand how the Trust's money is making a difference in the lives of people who have dementia and their carers. I understand that this information will be used anonymously.

Applicant

Signature

Print name

Date

Second applicant (if a joint application)

Signature

Print name

Date

Thank you for your application. Before sending, please check you have answered all the questions. **Please post or email to:**

(Partner agency details)

(Partner agency) will contact you within two weeks with a decision.

APPENDIX B – Applicant Guidance

The guidance was adapted by partners to include their name and logos as well as that of the Life Changes Trust and Big Lottery Fund Scotland.

People Affected by Dementia

Individual Awards - Guidance for Applicants

1. What are Individual Awards?

The Individual Awards project is a trial project which aims to give some extra financial support to people affected by dementia – both people with dementia and their carers.

The Life Changes Trust is offering small amounts of money to people affected by dementia to:

- spend on something that they think will make their life better
- enable them to do something that matters to them which, without the award, they would not be able to do

The Life Changes Trust is running the trial project to find out what benefits Individual Awards can bring to people affected by dementia.

Edinburgh/Argyll and Bute (insert area specific to partner agency) is one of the areas in which the trial project is being run. It will run from: 1 October 2014 to 15 January 2015.

People can apply for any amount up to £500 per person.

The money comes from the Life Changes Trust but is being delivered through

(insert partner agency's name).

2. What is the Life Changes Trust?

The Life Changes Trust was established by the Big Lottery Fund in April 2013 with a National Lottery grant of £50 million to support transformational improvement in the well-being and quality of life of people affected by dementia, including unpaid carers, and care experienced young people.

For more information, see the website: www.lifechangestrust.org.uk

3. Who can apply?

You can apply if you can answer YES to two out of these three questions:

- I live in **Edinburgh/Argyll and Bute (insert area for partner agency)** AND
- I have dementia, OR
- I care for someone with dementia for more than four hours a week and don't get paid for it.

Two people can apply for an Award together if they wish, for example, a person with dementia and the unpaid person who cares for them. They can apply together for up to £1,000.

You can only get an Award once.

4. What costs can Individual Awards cover?

You can ask for money to spend in a very personal way on something which suits your own situation and personal interests. Here are some **examples** of what you could apply for.

Something to make your home life better

- Re-decorating a room; new washing machine or tumble dryer; help to tidy up the garden

Something to improve your health

- Dancing classes; swimming pass; complementary therapies; counselling

Something to safeguard your future and your loved ones' future

- making a will or creating Power of Attorney

Something to keep up your hobbies and interests or let you try something new

- Arts and crafts materials and classes; garden shed, garden bench, plants and seeds; cinema or leisure centre pass; annual membership for visiting heritage gardens or historic buildings; travel costs to get somewhere important to you that you wouldn't otherwise be able to visit

Something to help improve communication

- Music player and downloads to listen to music and share it with others; mobile phone; computer to Skype with family and friends; internet access

Something to let you learn something new

- Learning to drive, swim, use a computer, play a musical instrument; training course to help you get back into the workforce

Some time away

- Cost of a short break or going to visit family that live far away

These are just **examples**. Everyone is unique and will have their own needs and interests.

5. Are there things the Life Changes Trust would not fund?

Yes.

The Life Changes Trust would not generally fund things which councils and health boards should pay for. For example, the Life Changes Trust would not pay for care services in the home if the council would normally pay this for you.

If you have questions, please contact (named person at partner agency) on (telephone number and email).

Each application will be assessed by a panel of people from the organisations who are administering the Individual Awards for the Life Changes Trust.

6. How do I apply?

You can obtain an application form from (partner agency). You can request a paper copy or ask for an electronic copy to be emailed to you.

Please note that the Life Changes Trust will ask you to give feedback on how the Award has made a difference for you. You will be able to do this in writing, or by phone or email, or through a conversation face to face – the choice will be yours.

The Life Changes Trust needs this feedback so it can understand what benefit the Individual Awards bring. The feedback you give will be anonymous.

7. When can I apply?

The earliest you can apply is 1 October 2014 and the latest is 15 January 2015. Applications will not be accepted outwith these dates.

8. What if I want to apply on behalf of someone who lacks capacity to do it for themselves?

If you are applying for an Award on behalf of a person who lacks mental capacity to do so on their own behalf, you must provide evidence that you have Power of Attorney for their financial affairs. You will be asked about this on the application form and, if your application is successful, you will be asked to show the original legal Power of Attorney document to (partner agency) before an award is given.

9. How is the Award paid?

The Award will be paid in the way you prefer. This will be done by (partner agency). It can be paid directly into your bank account or by cheque.

10. What happens to my application?

Your application will be reviewed by an Award Panel made up of people from (insert details). The Panel meets fortnightly.

The Panel may ask you for further information if your form is incomplete.

If your application is **successful** you will:

- hear within two weeks of the Panel's decision
- receive the money within three weeks of the Panel's decision
- have the money paid as agreed with you, either into your bank account or by cheque

Please note:

- As a general rule, you must spend the Award within **two months** of receiving it
- You must give receipts to **(partner agency)** to show that you have spent as the money as agreed
- You agree to give feedback to the Life Changes Trust about how the money has made a difference to you.

If your application is **unsuccessful** you will:

- hear within two weeks of the Panel's decision
- be given a reason as to why funding was not awarded

If you are unsuccessful the first time, you can make a second application for something else. You must do this before 15 January 2015.

11. Where do I send my application form?

Please submit completed application forms to:

(partner agency details – posting or emailing)

12. Concerns

If you have any concerns about how your application has been dealt with, please discuss this with **(partner agency)**.

If you still have any concerns about how your application has been dealt with, contact:

Elizabeth Morrison, Programme and Funding Manager, People Affected by Dementia, at the Life Changes Trust.

0141 353 4311

elizabeth.morrison@lifechangestrust.org.uk

Life Changes Trust
Empire House
131 West Nile Street
Glasgow
G1 2RX

Appendix C – Guided Feedback Letter

Date:

Dear Life Changes Trust,

I used the award to

.....
.....
.....
.....

It made a difference to me because

.....
.....
.....
.....

This really mattered to me because

.....
.....
.....
.....

Please add anything else that you would like to tell us

.....
.....
.....
.....

Yours sincerely,
Life Changes Trust Awardee

On behalf of the Life Changes Trust,

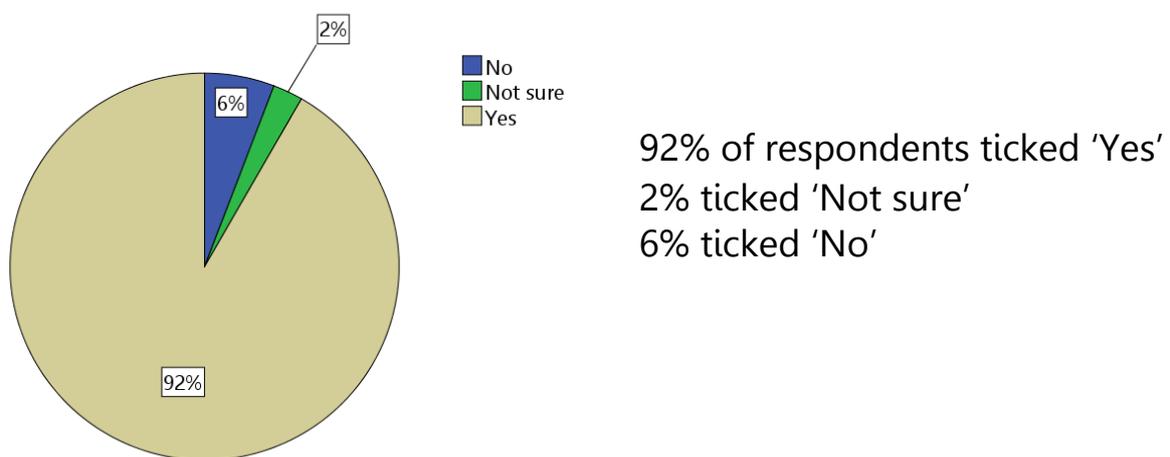
Thank you.

Appendix D – Summary of data from Guided Feedback Letter

Appendix D shows the breakdown of responses to the 'tick box' questions on the back page of the guided feedback letter (see Appendix C).

For each question there is a pie chart showing the percentage of respondents to that question who ticked each of the possible responses.

The Award is a one-off payment. Did it make a difference straight away?

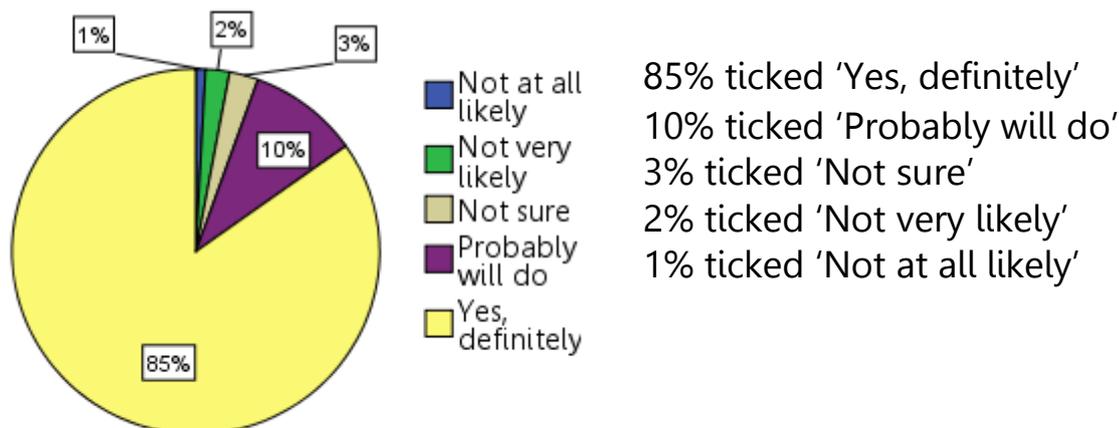


The cases where the respondent ticked 'No' or 'Not sure' were looked at more closely.

For the majority this was due to the timing of spending the Award (booking an item for delivery, waiting to go on a holiday, bad weather delaying garden work, etc.).

For some, life events or changes in circumstances delayed the spending of the Award. One person reported a long time between applying and the Award being made. At the time of giving feedback, one person was still trying to make up the difference to put the Award money towards a big project of garden work and redecorating.

Since then, do you think it might still make a difference in the next 6 months to 1 year?



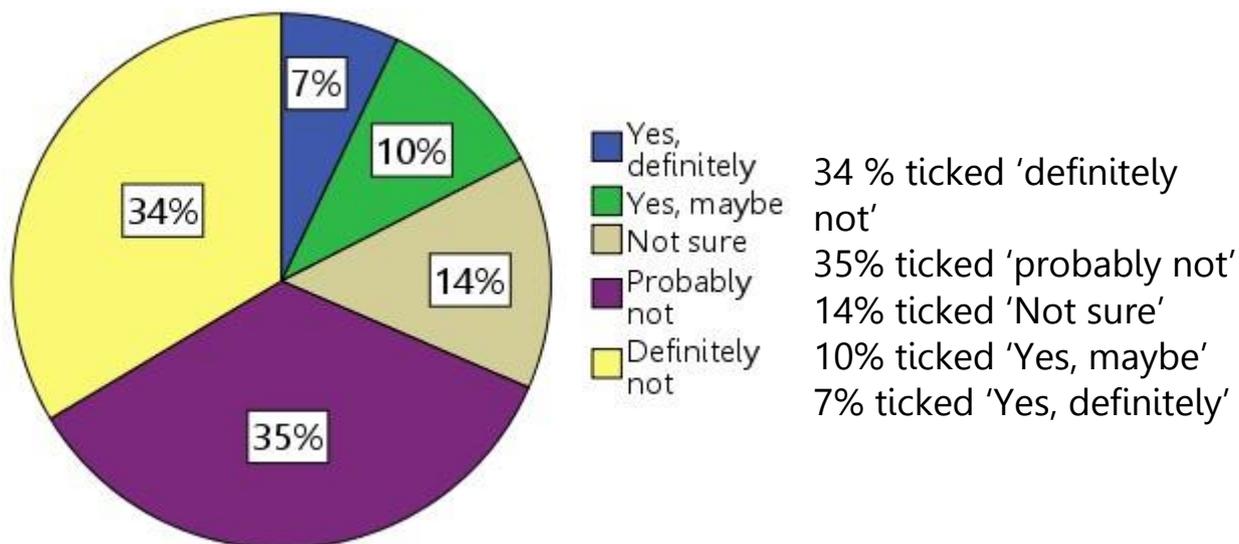
The 11 cases where the respondent ticked 'Not sure', 'Not very likely' or 'Not at all likely' were looked at more closely.

The majority of these 11 cases involved a holiday / short break or an outing where there was perhaps some doubt as to how long the memory would last for the person with dementia, or how long the relaxing and re-energising effects of the trip would last.

In one case a carer who had been in severe pain since an accident had used the Award for health care (massage and sessions with an osteopath). This person reported great benefit to health and well-being and consequently **"feeling so much better and more able to cope"**, but may have been unsure about how lasting the therapeutic effect would be.

In one case, the Award had been used to pay for redecoration in the home of a person with dementia, using contrasting colours to define the spaces, in the hope of maintaining independence. However, that person's health then deteriorated and the now spend most of their time in bed. The carer responded that it was 'not at all likely' that this use of the award would still make a difference in 6 months to 1 year.

Without the Award, would you have done what you did anyway?



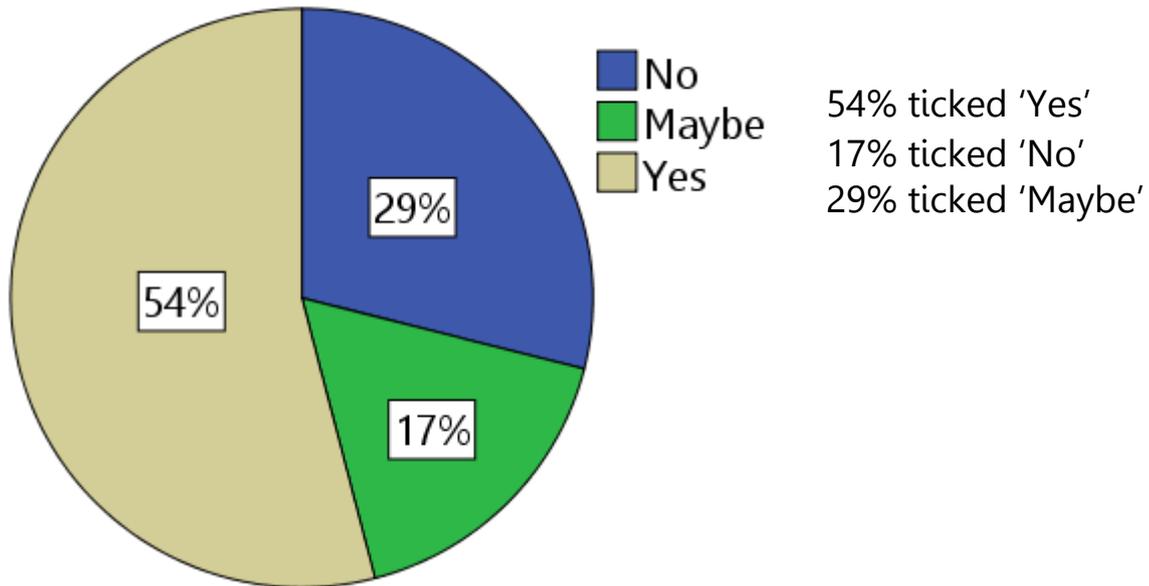
With regard to the question 'without the Award, would you have done what you did anyway?', many people in the 'definitely not'/'probably not' categories commented that, without the Award, it would not have been possible due to financial constrictions. Interestingly, a great many people referred very explicitly here to the motivating effect of the Award as well as the financial aspect.

The feedback from those who responded 'Yes, maybe' or 'Yes, definitely' was looked at more closely.

Where people would have, or might have, done the thing anyway, safety was often cited as a main reason. Others indicated that the items were badly needed and they would have made the purchase, but on a smaller scale, or saving for a considerable period to make it possible.

Sometimes health and care needs meant that time was of the essence (such as for intensive physiotherapy for a carer or for a high dependency chair). One woman bought laundry equipment to buffer the impact of her caring role on her own family, but would otherwise have gone into debt in order to achieve this. Occasionally people simply stated that they might have done it, or part of what they had done, anyway.

We may want to talk to some people in more detail about their experience. Please tell us if you would be happy to talk to us as part of a small group or on your own (you can have a friend with you).



This feedback indicates that it was important that provision of more detailed feedback was optional.

A considerable number of people ticked 'Yes' but specified 'Not in a group', indicating that this is also an important choice to offer.

APPENDIX E – Equalities Monitoring Report Summary

A full version of the report is available from www.lifechangestrust.org.uk

Overall

- **247** equalities monitoring forms were received.
- **Female** applicants significantly outnumbered male applicants.
- **Disabled** applicants significantly outnumbered non-disabled applicants.
- **'White Scottish'** emerged as the main ethnic identity. However, the pilot did succeed in reaching a small number of minority ethnic groups who were not targeted by the smaller MECOPP pilot. These included:
 - **1 'Pakistani, Pakistani Scottish or Pakistani British'** applicant
 - **1 'Arab, Arab Scottish or Arab British'** applicant
 - **1 'Gypsy/Traveller'** applicant
- The majority of applicants were **heterosexual** but the pilot did benefit **1 gay/lesbian** applicant.
- High numbers of equalities monitoring forms were received from older applicants aged **70-85**. Additionally, **7** equalities monitoring forms were received from applicants aged **90 & over**. **11** equalities monitoring forms came from younger applicants aged **30-44**.
- **'Christian'** emerged as the main religious identity. However, the pilot also reached a small number of **Humanist** and **Muslim** applicants.

Argyll & Bute

- **112** equalities monitoring forms were received.
- **Female** applicants significantly outnumbered male applicants.
- **Disabled** applicants significantly outnumbered non-disabled applicants.
- **'White Scottish'** emerged as the main ethnic identity. However, the pilot did succeed in reaching a small number of minority ethnic groups. These included:
 - **1 'Arab, Arab Scottish or Arab British'** applicant
 - **1 'Gypsy/Traveller'** applicant
- The majority of Argyll & Bute applicants identified themselves as **Heterosexual** and **Christian**.
- The majority of the applicants were in the **70 – 85** age range. However, a large number of equalities monitoring forms also came from applicants in the middle age bands (**55-59, 60-64** and **65-69**).

Edinburgh

- **135** equalities monitoring forms were received (including 10 from the smaller MECOPP pilot – see below).
- **Female** applicants significantly outnumbered male applicants.
- **Disabled** applicants significantly outnumbered non-disabled applicants.
- **'White Scottish'** emerged as the main ethnic identity. However, the pilot did succeed in reaching **1 'Pakistani, Pakistani Scottish or Pakistani British'** applicant who was not linked to the smaller MECOPP pilot.
- The majority of applicants identified themselves as **Heterosexual** but the pilot benefited **1 Gay/Lesbian** applicant.
- Age data was widely distributed across the spectrum. The majority of equalities monitoring forms were received from applicants aged **70-85**, but a number of forms also came from applicants aged **45-54**.
- **'Christian'** emerged as the main religious identity. **'No religion/None'** was highlighted as the second most common religious identity followed by **Muslim** and **Sikh**.

MECOPP (Smaller Pilot)

- **10** equalities monitoring forms were received.
- The **MECOPP pilot** within the Edinburgh region produced the following results:
 - **70%** of equalities monitoring forms were received from **Female** applicants
 - **80%** of equalities monitoring forms were received from **Disabled** applicants
 - **All** equalities monitoring forms were received from **Heterosexual** Applicants

The following ethnic minority groups were recorded:

- **4 'Pakistani, Pakistani Scottish or Pakistani'** applicants
- **4 'Indian, Indian Scottish and Indian British'** applicants
- **1 'Mixed Ethnic Group'** applicant

Getting in touch

If you have any queries or wish to share your views and ideas, you can contact us in a number of ways:

Phone: 0141 212 9600

Email: enquiries@lifechangestrust.org.uk

Website: www.lifechangestrust.org.uk

Address: Life Changes Trust, Empire House,
131 West Nile Street, Glasgow, G1 2RX