



**Individual Awards Scheme
Final report**

May 2020

Conducted for:



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Report Summary

The Awards

The Individual Award Scheme provided up to £500 for someone with dementia or someone caring for a person with dementia in an unpaid role. Those who received an Award could spend the money on anything that they believed would make a difference to them. They had up to a year to do this. Care and Repair organisations in Aberdeen, Locharaber and Angus (in partnership with other local organisations) were funded by the Life Changes Trust to administer the Individual Awards to people affected by dementia in their area.

Impacts

Wide ranging, long-lasting and far-reaching impacts were identified. They included benefits for physical and emotional wellbeing, ability to connect and interact with others, reduction in feelings of isolation, connection to other sources of support and financial empowerment.

Although the Awards represented a relatively small amount of money and were often spent on an apparently straightforward and practical need, the initial and immediate impacts had ripple effects. They led to positive impacts for family members and connected people with other forms of support. Impacts were often greater and more wide ranging than had been expected, encompassing emotional, quality of life and relationship improvements and potentially avoiding or delaying a need for more costly support.

Learning

A small amount of money spent on a straightforward benefit can help to support both people with dementia and unpaid carers to maintain their independence, improve their social connection and keep managing their lives in their home setting for longer. This contributes to a range of policy objectives in areas such as loneliness and isolation, connection, physical and mental wellbeing and housing as well as health and social care and self-directed support. It has an important contribution to make to the notion of preventative spend.

Freedom, dignity, choice and control are at the heart of policy thinking in the area of self-directed support for people with dementia and unpaid carers. The Individual Awards Scheme demonstrates that a model of a small grant, issued through a simple, trusting and supportive application process, with flexibility (to choose and to change decisions on spend) allows people to have control and to make decisions that maximise the impacts for themselves.

Applying this learning to the design and implementation of individual grant schemes and approaches to self-directed support should enable Health and Social Care Partnerships and third sector organisations to work individually and together to deliver simple, meaningful and impactful support to people with dementia and to unpaid carers. The key components to consider in the design of an individual grant scheme include:

- Broad criteria that cover anything that people know will make a difference to them
- A simple application process
- Support and freedom to consider what makes a difference, to complete the application and follow-up support if needed (for example to spend the Award)
- This support should come from a known and trusted person/organisation with an ongoing relationship with the individual
- Flexibility to make changes if needed.

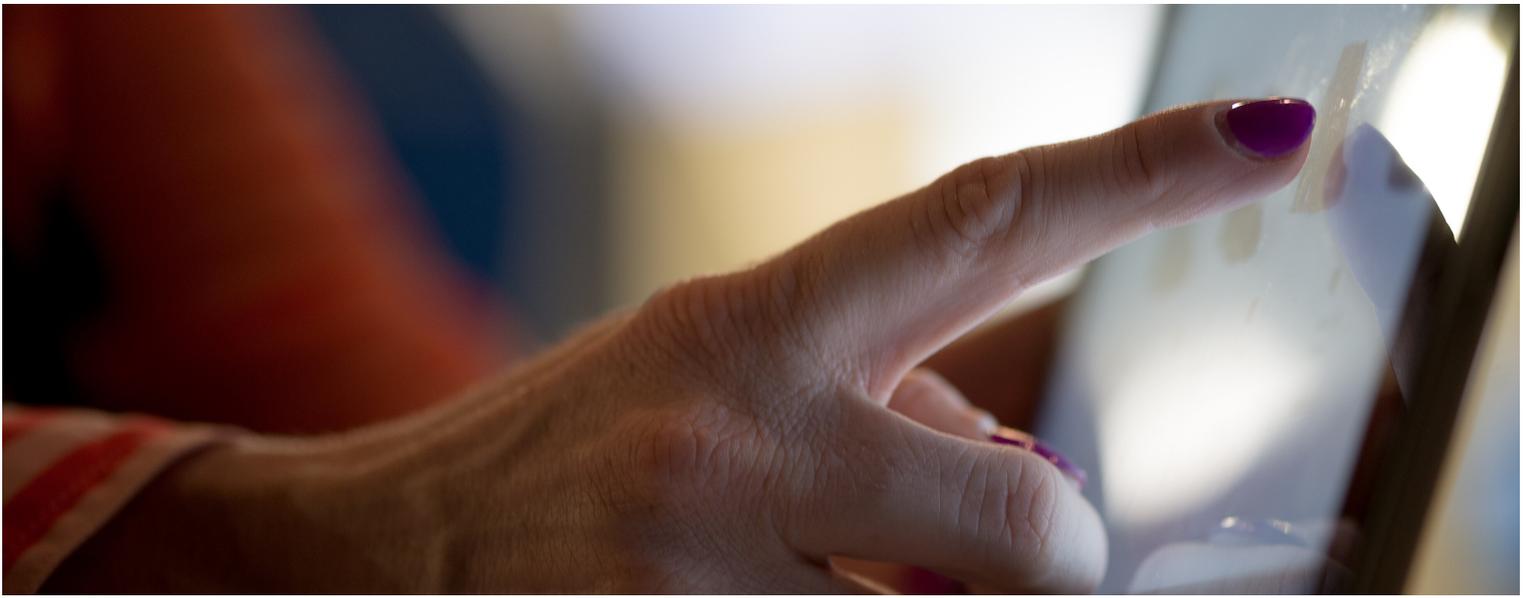
There are also links to public policy more generally and in particular, learning for policy and practice in the area of Self-directed Support and support for unpaid carers. To successfully deliver personalised social care support in Scotland for people living with dementia and unpaid carers in Scotland we need to ensure that:

- Those who are being supported feel in control of decisions
- The support is flexible
- Good, supportive relationships exist to help people access support
- People accessing support are trusted to know what matters to them
- Support is tailored to individuals and their circumstances.

Two stories

Here are two stories about the impacts of the Individual Awards Scheme¹.

¹ The names of the people in the stories have been changed throughout the report to protect their anonymity.



Strengthened bonds and shared joys: Anne's story

Anne lives in Aberdeen. She was 54 when she was diagnosed with dementia three years ago. Her close family live in Northern Ireland (where Anne was born) and the family share a huge, lifelong enthusiasm for motorcycle racing.

She and her husband used funding from the Individual Awards Scheme to purchase a tablet to stay in touch with family, and for a special trip to the TTs motorbike race on the Isle of Man. Anne still talks about the trip to the TTs: she realised a lifelong ambition and this has given her new memories and an ongoing topic of conversation with her family. She has a photo album and pictures on her walls to help her remember – an continuing source of pleasure. She lights up when she talks about the trip.

“ ***I've always followed the motorbike racing, I'm a big, big fan and you know in Northern Ireland I followed the Dunlop family for years and years and years and went to all the racing, and my biggest dream was to go to the TT on the Isle of Man and never could afford it and it was brilliant ...oh my God what an experience. It was fabulous I'll never forget it!*** ”

Balance can be a problem for Anne, and she has experienced getting very lost and confused when out on her own. Both of her dogs died recently so she no longer has their company during the day. She doesn't get out much now and she was feeling lonely and isolated, with little human contact while her husband is out at work.

“ ***I'm here in the house all the time, I don't go out at all... I get nervous out now because I'm afraid I'll fall... I'm in the house 24/7.. I'd be scared of getting hit on the road or anything, I've no sense of the road or anything now, no sense at all.*** ”

Anne found it difficult to stay in touch with her family, but now, with the tablet, she can see them every day. The tablet also allows her to continue to follow her motorbike racing heroes, giving her joyful ways to pass her time at home.

“ I can talk to my wee granddaughter... but honest, see since I got that tablet I've seen more of her because I don't travel too much now...It keeps me connected to everybody really, it's brilliant and it's got some good music and videos and I watch the re-runs of Joey Dunlop and all, I watch all that stuff so it's made a big, big difference...I feel less isolated I suppose...I'm here all the time but since I got that I've been able to watch YouTube.

The benefits of both the trip and the tablet purchased with the Individual Award are long-lasting.

“ Those two things were the best things happened to me, I can say, for a long, long time. The TTs trip is not something I'm going to forget. It's not a wee fly-past thing it's a lasting thing for me.

I'll have this [tablet] for years ...it keeps us all together... you can do like multi-frames or chats so me, Jess and Elaine [Anne's sisters] would get together sometimes and it splits in three so we're all chatting to each other and we can all see each other, and it's brilliant because I'll not be able to get home as much as I want now.

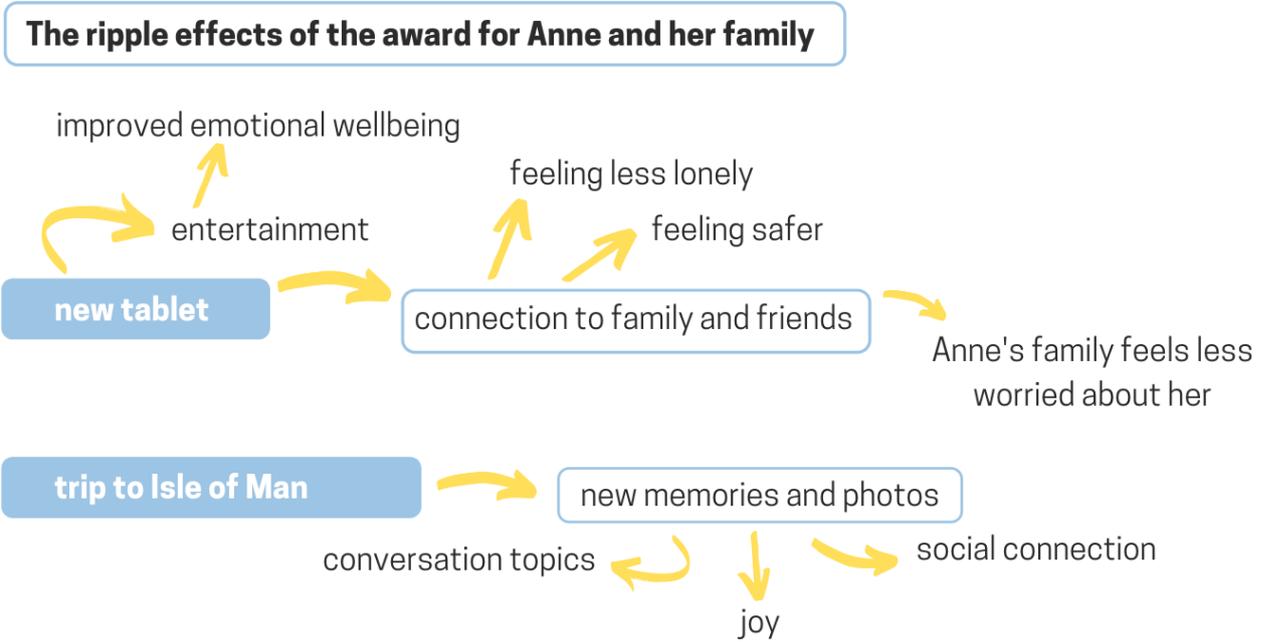
The benefits are also far-reaching: for Anne, for her husband (who worries less about her while he's at work) and for her family back in Northern Ireland.

“ It's benefitted everyone that I love, everyone that's important to me. It's kept me in touch with my family, I'd never have been able to afford [the tablet and trip] unless I saved, which I can't save because I'm only on PIP.

For Anne, the impacts of this small amount of money have been enduring. She reaps them still, on a daily basis. Her life is being enriched and her mental health supported in important, ongoing ways.

“ It's made such a big impact on my life...I know that some people think £500 is nothing but it is to some people - it was to me. It got me a lifetime holiday away you know, and I'm in touch with my family every day and I wasn't before.

The diagram below shows how Anne’s trip to the Isle of Man and new tablet had impacts beyond the immediate and obvious benefit, rippling out to her wider family and her own feelings of connection, safety and joy.





One thing leads to another: the Johnson family's story

Bill cares for Lizzie, his wife, who has dementia. They live at home in Angus. In addition to looking after Lizzie, helping her to dress and keeping her entertained, he takes care of the shopping, cooking, cleaning and gardening. Bill describes her as having the 'happy kind of dementia' and they tease each other affectionately and laugh a lot together.

They used their award towards the cost of some help with cleaning and gardening. Bill's reason for this was so that he could spend more time with Lizzie. He had been finding it more and more difficult to keep her safe while he got on with doing the things that needed done. He was worrying about what might happen if he couldn't cope.

“ The letter explained that we could use it for this, that and the other, there was a lot of things there but we eventually decided it would be better to save me from doing the gardening and cleaning because if I'm not here then she'd be... because she'd be put into a home somewhere.... The things we thought would be the most beneficial to keep us together, you know we do things together when they're doing that. (Bill)

The Johnsons are a friendly couple but were finding it hard to spend time together and to socialise because of the calls on Bill's time and energy just keeping the house and garden in order. Now they have more time to enjoy each other's company and to see other people.

“ It's made a big difference to us because we're now spending more time together, we can go out now. You know we don't have to stay in and do the Hoovering or things like that, on a nice day we can just go out. So, we went down to the golf club this morning, sat and had a coffee and a blether with the folks down there, so we wouldn't be able to do that if I had to do the cleaning or the gardening. (Bill)

“ I didn’t want him to have to go upstairs and clean and do the next thing, but I used to do that. I used to do all that and cooking and so for a while I was a bit, well he’s away up there and he’s away here and I’ve got to sit here until he comes back wherever you know. (Lizzie)

Their daughter Cath helped them think about how to spend the award:

“ And you know, we’d maybe spoken before about, you know, “why don’t you give yourself a break? Why don’t you get cleaners?” It’s a relatively big garden, but they both enjoy it, they both like being out there, because they spend a lot of time there at the summer house, on nice sunny days, and things like that which is why he likes to keep it up. (Cath)

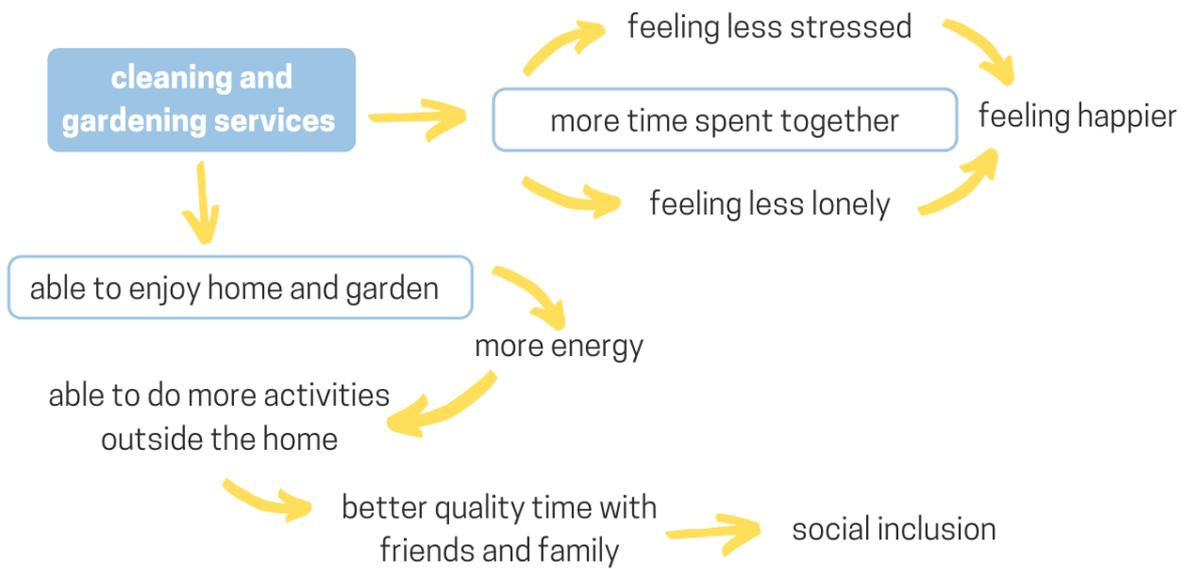
Help with the cleaning and gardening has had wider impacts than any of them expected. Bill feels less stressed, Lizzie is enjoying the extra social time and Cath has noticed her dad is less tired and more cheerful. As a result, they were all more confident about the couple’s ability to keep on coping with living at home together for longer. At home and together is where they both want to be for as long as possible and the award has helped them to keep achieving that.

“ It’s brought us closer together because you do get a bit irate when you’re doing gardening and Hoovering and the washing and things like that, it does get on top of you and you could lose your temper occasionally, but that doesn’t happen now... (Bill)

“ I would certainly say stress levels are reduced. He doesn’t seem as tired. Because often sometimes when we were there before, he would be starting to nod off in the chair now he’s not as much like that. (Cath)

“ I feel good, he’ll say ‘och we’ll go down there and we’ll see so and so and we’ll see so and so’ and I do like being with him, I just don’t know what I’d do without him. (Lizzie)

The ripple effects of the award for the Johnson family



1. Introduction

What is the Individual Awards Scheme?

- 1.1 The Life Changes Trust is committed to enabling, protecting, supporting, valuing and empowering people living with dementia and their unpaid carers. The Trust wanted to find out whether giving people living with dementia and unpaid carers a relatively small amount of money to spend on something chosen by themselves would make a difference to their lives.
- 1.2 This approach was tried by the Trust in a pilot project in Argyll and Bute and Edinburgh in 2014-15. People living with dementia or caring for someone with dementia could apply for an Award of up to £500 to spend on anything that they believed would make a positive difference to them. The pilot project had a really positive impact for the individuals who received the money. It also helped local organisations who support people affected by dementia to get to know each other and the people they support better.
- 1.3 So, the Life Changes Trust decided to run the Scheme in three new areas during 2018-2019. Care and Repair organisations in Aberdeen, Lochaber and Angus (in partnership with other local organisations²) were funded by the Trust to administer the Individual Awards to people affected by dementia in their area.
- 1.4 The Trust wanted to learn more from this about how people affected by dementia can be supported. It is hoped that this learning can help to inform how support for people with dementia and unpaid carers is developed and provided in future and can inform important policy areas like Self-directed Support.

² Alzheimer Scotland and Angus Carers in Angus
Connecting Carers, Voluntary Action Lochaber and Care Lochaber in Lochaber
Age Scotland and In control Scotland in Aberdeen

602

people received awards

£467

was the average award

Half of the awards were given to people with dementia and half to carers

people spent their awards on...



33%

Home renovations and gardening



27%

Trips, breaks and experiences



26%

Furniture and appliances



14%

Other e.g. transport, activities and mobility/sensory aids

49%

said that the award let them do something they would not otherwise have done

96%

felt the award made a difference to them straight away

89%

felt that it would continue to make a difference in 6-12 months

those who received an award...



63%

Noticed an improvement in their practical quality of life



58%

Experienced greater emotional wellbeing



25%

Felt better connected

How does Scotland support people with dementia and unpaid carers?

- 1.5 Self-directed Support is Scotland's approach to social care support. This is the way that social care (help with managing day to day life) is delivered to people who need it, regardless of their age, their diagnosis or why they need support. It includes support that people with dementia might need. Unpaid carers of people with dementia are also eligible for Self-directed Support in their own right.
- 1.6 At the heart of Self-directed Support is the idea that the person who needs support makes choices about how, when and in what way that support is provided. For people with dementia and unpaid carers of people with dementia, this means having the right information, advice and help so that, as far as possible, they are able to make decisions about their own support.
- 1.7 A person who needs support should be at the centre of decision making and should be treated with dignity. They should have the right and freedom to make choices about their support and to have control of their support, as far as they can. These rights and principles apply even when a person has difficulty making choices or deciding or describing what really matters to them. In this case, they should have encouragement and support to do this from people who know them well.
- 1.8 The legal basis for self-directed support is the Social Care (Self-Directed Support) (Scotland) Act 2013 which came into effect in April 2014. This is national legislation which applies equally across Scotland. It is underpinned by a national implementation plan issued by the Scottish Government.³ Everyone accessing support, including people with dementia and unpaid carers of people with dementia, has the same rights under this legislation. This includes the right to be offered the four options of Self-directed Support.
- 1.9 Formal evaluations and reviews of Self-directed Support and feedback from people accessing support, tell us that people do not always get the freedom, dignity, choice and control the legislation and policy entitles them to. There is still much to do to make Self-directed Support work well for people with dementia and unpaid carers of people with dementia.
- 1.10 The Individual Awards Scheme described in this evaluation report did not replicate all of the elements involved when someone is directing their own support through the national Self-directed Support policy. However, the Scheme used the same principles and practices of good Self-directed Support.

³ <https://www.gov.scot/publications/self-directed-support-strategy-2010-2020-implementation-plan-2019-21/>

This includes, for example, focussing on what really matters to the individual and how best they can use the resources available to them to make the most positive difference in their life. It means ensuring freedom, dignity, choice and control.

- 1.11 Understanding the impacts of an Award scheme like this adds to the growing body of knowledge and evidence about what makes Self-directed Support work well. This can contribute to people being able to genuinely direct their own support in the ways that make most sense to them and enable them to live a good life.

What is this report about?

- 1.12 This report describes the impacts or differences the Individual Awards made to the lives of the people who received them in Aberdeen, Lochaber and Angus. Appendix 1 shows that we gathered evidence by looking at monitoring information and feedback, and by talking to people who received an Award through the Scheme.
- 1.13 The report describes what can be learned from this approach to Individual Awards. We explain how this learning can be used to better support people with dementia and unpaid carers in future.

33%
spent their Awards on their home
or garden

8%
home repairs



5%
redecorating



3%
flooring or carpet



12%
garden

27%
spent their Awards on trips,
breaks or outings



11%
short overnight
trip or weekend
break

10%
holiday



3%
outing or day trip

3%
visiting friends or family



26%
spent their Awards on furniture
and appliances

5%
chair or sofa



4%
TV or DVD



3%
bed, mattress
or bedding

phone or
tablet **4%**



In addition, 14% of people spent their Awards on other things like transport, activities or mobility and sensory aids. The graphic shows the types of spend which made up 3% or more of Awards.

2. What we learned about impacts

What were the Awards spent on?

- 2.1 Awards were granted for a very wide range of uses. These are summarised in the graphic on the previous page. Use of an Award for home or garden purposes were most common, making up one third (33%) of all Awards. Garden was the most common single category across the Scheme (12% of all Awards). Just over a quarter (27% of Awards) were for different types of trips, breaks or outings. The third most common Award type was to purchase or replace furniture or appliances⁴.

What were the impacts for people who received an Award?

Emotional well-being

- 2.2 The Award led to improved emotional well-being for many people in a variety of ways. Almost three out of five (58%) said their Award helped with emotional well-being, which was higher than the 48% who expected the Award would have this impact when they applied for it. Over a quarter felt more included (more than double the 11% who expected this) and 10% felt more empowered (compared to 8% who expected this).
- 2.3 Sometimes this was a direct result of spending the Award on enjoyable learning experiences, for example, piano lessons. Some people spent the Award on a special trip with loved ones, and this helped to lower stress levels and improve relationships.
- 2.4 Others chose to spend the Award on something that helped to remove stress or worry about a specific thing. For example, the Award provided peace of mind for people who used it to replace essential household items, such as cookers, washing machines, boilers, TVs or freezers. Usually these were items that people relied on day-to-day but were old, expensive to replace and causing worry about what would happen if they broke down.
- 2.5 Some people spent the Award on items that brought them ongoing pleasure, such as a DVD or music player. One couple were delighted to be able to go for walks together again after spending the Award on a power pack for their wheelchair, which was otherwise too difficult for the carer to manage.

⁴ In addition, 14% of people spent their Awards on other things like transport, activities or mobility and sensory aids. Please note the above graphic only shows types of spend which made up 3% or more of Awards. A full breakdown of everything people spent their Awards on, is in Appendix 2.



“

I like to be in the shed; it gives me a job and it makes her happier.

Alan

Alan and June's Story

Alan and June had to move from their house in town to a flat. Alan had always enjoyed the garden, and in particular the shed, where he spent many happy hours 'pottering'. They used their Award to buy a new shed, exactly the same as the old one. They had this shed installed next to their caravan by the sea, where they like to spend time as often as they can. This is particularly important to them now that they do not have outdoor space at home. Alan has anxiety and 'prowls' when he is feeling that way. Since they got the new shed, he has been much calmer and more relaxed again. June suggests a job for him to do every day and he enjoys himself in the shed getting on with it. This gives June time to herself, just to read her book, have a cup of tea and relax.

“Even though I say, ok, what'll I get him to do, you know I've got to think, but then he knows, he just goes out and potters, even if it's just cleaning the shelves.

“When he's out there I've got me time, inside. Whether I'm reading or doing normal housework things because we're together 24/7 we don't have a break, there's nobody to help us and sometimes I feel so down, I can't get out. That hour or hour and a half or two hours is lovely, and I'm sure he feels the same too, being together 24hrs, you have to get a wee break.

2.6 Some unpaid carers used their Award to cover the cost of respite care to give them a break from their caring role. These unpaid carers said the experience re-charged their batteries or gave them a rare opportunity to spend time with their own families. For example, one carer said that having had a break with her husband gave them time to devote to their own relationship, which had been suffering from the stress of looking after her mum.

“ I was getting so stressed out, about my own health and everything. And we got mum into respite, for a week. So that we could go away. I was just getting really, really depressed.

Unpaid Carer in Aberdeen

2.7 Unpaid carers returned from a break feeling less stressed and able to cope with caring again. One carer commented that she “began to remember how other people live” which illustrates just how isolating and stressful caring can be. Decreased stress resulted in increased patience, calm and tolerance towards the person they cared for. Wider family members who commented recognised the benefits of this respite for carers.

2.8 The quotes below from unpaid carers who used their Award to have some time away, demonstrate the scale of the impact this can have.

“ I didn’t think I would get to feel as good as I did. Because it’s such a worry, and then I knew she was going to be looked after, and I didn’t have to worry about her. So, I could go.

Unpaid Carer in Aberdeen

“ It’s very difficult you know...but if you’ve got to do something you just do it, I don’t mind looking after my husband at all but the break away is amazing.

Unpaid Carer in Angus

“ It gave us quality time together, my husband and I, we could talk about whatever we wanted to, we could go where we wanted to, we could please ourselves what we did, whereas we can’t do that when we’re at my mum’s, it’s really hard, so that few days away just sort of recharged our batteries.

Unpaid Carer in Angus

“ I felt absolutely brilliant because I got away from it all... and just having time with my husband, just the two of us. Because we don't get time together, at night-time, mum's always wanting me there... and she expects my husband to do everything for her as well. And he doesn't have a life with her either. You know, she's demanding ... so he was getting a bit down too.

Unpaid Carer in Aberdeen

2.9 Some couples where one is caring for the other took a break together. These people really appreciated the opportunity to spend time together away from the day-to-day. It meant they could spend time with each other away from the home environment and all the usual jobs and stresses.

“ You've no cleaning or gardening, washing or cooking just all the things that takes up my time here, like I canna spend so much time with my husband because there's aye something, you know in the garden or the house but when you're on holiday you get to spend all the time together and you don't have to rush to do this or that. You've nothing to do really, just relax.

Unpaid Carer in Aberdeen

2.10 People told us that spending the Award on a break or a change of scene had impacts on relationships within their wider family. For example, a couple who were caring for a parent used the Award for a break together while a sister came and took over the caring role.

“ It helped everybody because myself and my husband were refreshed and she was pleased we were back...she had a special time with my sister as well, doing different things with her than she would do with us.

Unpaid Carer in Lochaber

2.11 Money spent on improving the home environment, such as decorating, a new carpet or gardening also impacted on emotional well-being, for both the carer and the person being cared for. We heard an example of a woman who was no longer embarrassed to have visitors after spending her Award on redecorating her front room.

2.12 A member of staff in Aberdeen commented:

“ It’s actually quite surprising, some of the things you wouldn’t think would make that big a difference actually do. And not always just the people who have dementia, but even the carers, especially if it was for things maybe like a break away. Or, redecorating or something like that. Having that little break or a little project for them seemed to be such a big help, mental health wise. I noticed quite a lot of people commented on that.

Staff member



“

We have loads of photos and she's absolutely beaming, it's fantastic.

Betty's daughter

Betty's Story

Betty used her Award to pay for a new walking frame. She is unsteady on her feet and her family worried about her falling. Betty loves to go out and about, but her family mostly took her places in the car because it was safer and easier than going anywhere on foot. Most trips out were for essential things like going to the supermarket or the doctor, not for pleasure. But they worried that this was not the best thing for her because she was missing fresh air and exercise. Now they go out for walks with her and Betty is more confident to get out and about again with her 'wheels'. Betty's daughter shares her thoughts:

We're taking her for more fun things. You know my brother he goes down and takes his dog and they go for a walk round the block with the little dog whereas before she'd just be like 'oh no, I'm fine I'll just stay here'. We all feel more confident going out with her because we feel like she's safer and she's more able to be steady on her feet.

We've taken actually lots of photos of her with her wheels because we have a family group chat - we've called it 'Mum's the word' so we share you know all the stuff that we're doing so we send photos to the group chat showing Mum out on her wheels.

Physical well-being

- 2.13** There were numerous examples of the ways in which having choice and control over how to spend a small amount of money had an impact on physical well-being. These included, new chairs, beds and mattresses relieving sore backs or other ailments, a new carpet removing the risk of tripping in the home, decking or smooth paths meaning that people could enjoy their gardens or hang out their washing safely again. One person explained that having a new freezer gave them time to go for a walk and to benefit from fresh air and exercise rather than having to go to the supermarket.
- 2.14** As you can see from Betty's story above, a physical impact often has a 'knock-on' emotional impact as well. Betty is physically benefitting from more exercise and fresh air. She and those who love her are also benefitting emotionally from less worry and the joy that this new freedom brings her.
- 2.15** One couple in Angus used their Award to have a smooth path made in their garden. It was difficult to get the wheelchair outside previously along the gravel path. They can now spend much more time sitting out enjoying the physical and emotional benefits of the garden. Mary benefits from more sunshine and fresh air and her unpaid carers benefit from less physical exertion and risk of injury. Everyone is also benefitting emotionally.



We have a ramp down the steps that we take Mary down into the garden on a nice day in her wheelchair and it's made it so much smoother. We had her out when we had the good weather over Easter and were able just to roll her over the garden and into the grass without having to struggle and pull, so very beneficial.

Unpaid Carer in Angus

- 2.16** It was clear from almost every example that we came across that physical well-being also affects emotional well-being. Unpaid carers worry less from knowing that their loved one is safer or in less pain, or able to do something for themselves again. People with dementia gain confidence to do things again that they had previously needed help with. This affects feelings of independence, choice, dignity and control. People who have had garden improvements benefit physically by being better able to safely use their outdoor space and from more exposure to sunshine, birdsong and the outdoors. They also benefit emotionally from the fresh air, enjoyment and relaxation.

“ I know with the chair now, she’s comfortable, it’s easier for her to get in and out of. And she can have a little of sleep in it, she can put her head back and that. Which is good. And the footstool is very good for her keeping her feet up, which is important too.

Unpaid Carer in Lochaber

“ It feels a lot better because as I say I’m nae quite so worried about going out in the back now, I just didn’t seem to have the confidence for a while, I only had to trip once and that put me off you know. But I think I’m getting, my head’s getting a wee bitty mair, it’s no so muddled up as it was, so you can sit out there and just relax and nae sense of bother.

Person with dementia in Aberdeen

Practical help

2.17 People with dementia and unpaid carers often struggle with managing jobs around the house and garden and some of the Awards were used to pay for help with these things. Examples include gardening and housework. Sometimes the Award prompted people to get ongoing help with these tasks that otherwise they would not have done. In other cases, the Award paid for specific jobs, like painting a coal shed or cutting back some troublesome bushes. One fifth (21%) of all Awards were used for home improvements, 12% for gardening and 7% for household appliances.

“ The gardening, well that was actually another godsend for both of us. And because, neither of us can garden anymore, and we have to pay for the chap to come and do it all. So just to have that you know, that money for him to do what we wanted to, was absolutely fantastic.

Unpaid Carer in Lochaber

2.18 Again, this sort of help had lasting impacts that improved emotional wellbeing: people were able to relax and enjoy their gardens again. The story of Bill and Lizzie at the beginning of this report illustrates how help with gardening and housework freed up time to spend together doing social things and led to reduced stress levels and better social contact outside their home, giving them more to chat about at home as well.

“ Yes, and we can just sit and chat and sit outside if it’s nice and we don’t have to bother about doing bits and pieces around and that’s a huge, huge benefit to me.

Unpaid Carer in Angus



Wonderful, because there's nothing worse than having an awful looking garden. You know, you are on edge, because you can't do it.

Unpaid Carer in Lochaber

Staying connected

- 2.19** Some people spent their Award on technology such as a new TV or a tablet. Just under one in ten (8%) of Awards were used for this. We heard how important these things can be to someone who does not get out of the house very often. One unpaid carer explained that his mother had deteriorated significantly in her mood and willingness to socialise during a period of time in hospital without the stimulation of TV. Her Award was spent on a new TV and she now has lively discussions with him and her carers about programmes she has seen and plans to watch.
- 2.20** An unpaid carer commented about the benefits to her husband (and as a result to herself) of a new iPad bought with the Award. She can get on with the things she needs to do without worrying about him and they have something to chat about (what he's watched on it) later over a cup of tea.



I can get on with things I need to do. And I know he's quite happy. And he's not agitated. It makes a big difference to me...He calms down completely, and sometimes I put on comedy things, like Only Fools and Horses and all that. He loves all that, he laughs away.

Unpaid carer in Lochaber

- 2.21** For others, new memories were made or old memories revived through trips away to special places. A woman took her husband (who is terminally ill) to the USA to see their son for the last time, using the Award to pay for expensive insurance and relieving her worry about what would happen if he was ill whilst away.
- 2.22** A man who had been in the RAF was able to use his Award to pay for himself, his wife and family to attend a ceremony where he was receiving a certificate for his role in recovering the bodies from an American plane that had crashed during the war.
- 2.23** Another woman used the Award to pay for a hotel so she could take her mother for a trip to Dundee which she had been asking to do for a while: Dundee held fond memories from her mother's past.



“

I think it's given us something, not just reliving the old memories but it's given us some new ones.

Isobel

Paula and Isobel's Story

Sisters Paula and Isobel used their Awards towards a trip to Jersey where their mother had grown up and they had visited frequently with her during their own childhoods. Paula lived in Ireland, but when she was diagnosed, she moved to Lochaber to be nearer Isobel. They describe Jersey as Paula's 'spiritual home'. On their trip to Jersey, they visited old haunts, remembered family and friends and even got invited into the bungalow their Aunt (who had brought their mother up) had owned and where they had many happy memories. They saw family they had not seen for a long time and had been finding it difficult to keep in touch with.

Well some of the people I could remember from much longer ago, you know we don't keep in touch, you know busy lives and everything. In fact, I bought a whole load of stamps I was going to send to lots of people but I find even that now too difficult so I can't keep up with people. Paula

We used to have all our summer holidays there as children and we had found some old photographs and we thought we must re-enact this photograph, so it was lovely! And, we laughed a lot! Isobel

He invited us in and gave us a guided tour of the cottage...the garden shed was still there, and the fruit trees were still there and ...I had planted some of them. Paula

What we've taken away from it is the sort of joyful memories that we had of being there, I don't think we could have asked for much more. Isobel

Did people use the money for something additional?

2.24 It was clear that the Award helped some people to think about doing something that they would not otherwise have been likely to do. Half (49%) of Awardees said this was the case. Even where people spent their Award on something they might have done anyway, the Award allowed them to do this sooner or to more easily afford it.

2.25 Those who spent their Award on ‘necessities’ like new bedding, cookers or TVs might have replaced these items themselves at some point but would have bought poorer quality items or waited till there was a crisis caused by something breaking down. The Award therefore avoided potential financial stress and worry/anxiety for these people. Having this financial wherewithal was a great relief to some of these people.

“ I don’t think that he would’ve thought about it at all. I think that my dad’s just the type, the age, just accepting just carry on. And just batten down the hatches and just try to keep going.

Family member in Angus

2.26 Other people used the money towards replacing household items that they worried were going to break down and make life very difficult. This brought peace of mind. These purchases included TVs, boilers, washing machines, tumble driers and so on: all things that are very important to people who spend a lot of time at home and rely on hot water, a warm home and being able to do frequent washing.

“ I was kind of thinking, would I wait until this thing breaks down, or will I be proactive and get a new one now. I now have peace of mind that my boiler isn’t going to conk out at the most inconvenient time. So it was well worth it for peace of mind.

Unpaid carer in Aberdeen

2.27 For many of the people we spoke to, the Award was spent on something they felt they would not otherwise have been able to justify spending money on: something they viewed as a ‘treat’ or luxury. The sense of this being a treat, something they would not otherwise have, was very real for some unpaid carers in particular.

“ Carers do need these, they really do, there’s not a lot of support until the person you’re caring for becomes incapable altogether. It’s fairly relentless, so any little chink is great and it’s not to do with the money. I could have paid that, but that would have meant not having something

else, that's what's nice, somebody says here you are, here's £500, you don't have to worry then that its coming out of your budget when you've got the electric to pay and all the rest of it, so it takes the pressure off.

Staff member

- 2.28** Some purchased new household appliances. Several people bought new, lightweight vacuum cleaners that helped when it came to housework, or simply made it possible for them to manage housework themselves.

“ The cleaner that we had, it was a huge heavy thing. What we now have is one of these modern, Dyson things and well, we can both get on with that it's just its brilliant, and we certainly could not have afforded to go through all that ourselves.

Unpaid carer in Angus

- 2.29** One man caring for his wife in Aberdeen spent the Award on a new cooker, which is much easier to keep clean and saves him time. He now cooks more meals from fresh than he did before, with health benefits for himself and his wife. Others bought items such as new beds or chairs that improved their comfort or pain levels, but that they would not have spent scarce money on themselves. One lady caring for her husband paid for new glasses that she had been needing for several years but could not afford.

- 2.30** Those who spent their Award on activities, travel or hobbies, were often doing something they would not otherwise have been likely to do, either because they couldn't afford it or because there were other more 'pressing' calls on their finances. This Award encouraged people to do things they had dreamed about, or not felt able to do for many years.

- 2.31** For example, one couple used the money they received to pay for a big family party for their 60th wedding anniversary. The money meant they could afford a meal in a nice hotel for the whole extended family and some new clothes to wear for the occasion. This was a special event for the whole family and the photo albums are treasured and looked at often. For some people the Award enabled them to have a last opportunity to go on a trip or to an event.

“ Getting everyone together all in the same place was unusual. That was the highlight for him as well because we probably wouldn't manage now it would be too much because all the fuss needed for having a meal out it wouldn't be the best now.

Unpaid carer in Aberdeen

2.32 It is clear that the Awards provided the flexibility for people to identify something that would make a difference to their life, that they would be unlikely to access otherwise and the freedom to apply for that without the constraints on eligibility that often apply to grant schemes.

Did having an Award help with independence?

2.33 Independence was a concern for many people with dementia and unpaid carers. It was seen as a really important part of maintaining dignity and quality of life. Many people talked about how the Award had helped with improving independence. For many of these people, the Award meant that they could remain independent for longer. Others had been able to get back some independence that they had lost. A quarter of the people who received an Award (26%) said that their Award helped them to feel more socially included and one in ten (10%) felt more empowered.

2.34 Some people spent their Awards on items to help them manage day-to-day life. This included riser chairs or walking frames which made moving around their home or neighbourhood easier. Others put their Award towards renovations to make their home easier for them to continue to live in, such as wet rooms or specially adapted toilets.

2.35 For example, a couple in Lochaber put the money towards having their bathroom converted so that the husband can now shower rather than bathe and no longer needs his wife's help.

“ I know he won't fall out the bath or be stuck in a bath and although obviously very aware of when he has a shower, he doesn't need any help. Oh yes, he can just walk into that shower and I'm sure he is happier - he doesn't say very much but he likes having the shower there and he likes to be independent.

Unpaid carer in Angus

“ My wife is more confident now that I'm showering now and she's not listening for loud bangs from the bathroom.

Person with dementia in Lochaber

2.36 For a woman in Angus dealing with the early stages of incontinence, a downstairs toilet has improved her daily independence, emotional well-being and made her daughter's and other carers' lives easier.

“ It’s a big thing for me because it means less washing, you know, I think that if the downstairs toilet wasn’t there you’d be classing my mother as totally incontinent and I would be washing every day. Because of the downstairs toilet, she’s not so much in any danger now of wetting herself, which means she doesn’t have to try and change herself, or to wait until the carers came in and that would distress her, that would really distress her, my mother was always very fastidious.

Unpaid carer in Angus

2.37 An Award spent on a new mower has meant that one proud gardener, caring for her husband, can keep her garden looking nice without the help of her family.

“ It meant that I was independent...that I didn’t need any of my family to come and cut the grass. Because I’m a keen gardener, so I like to keep it. And my husband just couldn’t do it anymore.

Unpaid carer in Lochaber

2.38 Independence was made possible for other people through the purchase of a walking frame, a freezer and many other items. And many carers commented on the impacts that this had for confidence and happiness in day to day life.

“ It’s all about being able to look after her in the home and it’s also about maintaining her own independence while she still has that.

Unpaid carer in Aberdeen

“ She is a very independent woman and she lost my father about 13 years ago and even up until the time she was diagnosed with dementia she was very independent...rather than us doing everything for her she’s wanted her own independence and to look after her own home and things like that so really the Award has certainly helped that definitely.

Unpaid carer in Aberdeen

A stitch in time saves nine

- 2.39** People told us that the relatively small Award, which could be spent on something that would make a difference, sometimes helped them to avoid needing other sorts of help, at least for a while. For some, it helped them to manage daily self-care or to live in their own homes for longer through adaptations or safety improvements that might prevent falls or other accidents (such as a wet room or safer access to their garden). In this way, the Award has potential to prevent or delay the need for more costly support from health and social care services.
- 2.40** There is also evidence of benefits in terms of pain levels, mood, reduced stress, improved relationships and improved social connection. All of these things can contribute to well-being and reduce the need for other forms of support.
- 2.41** New dementia-friendly phones helped to put unpaid carers' minds at ease by enabling the person with dementia to go for a walk by themselves or with their dog, helping them to keep more physically fit for longer than they might have otherwise.
- 2.42** Something as simple as extra bedding and a better washing machine can save an unpaid carer time, money and stress, enabling them to feel more relaxed and able to spend social time with the person they care for. Staff told us that this leads to emotional benefit for both the carer and their loved one and helps to avert crisis points in relationships.

“ It's ...also taken away some friction from certain people so there's been things like that that wouldn't necessarily come up in the evaluation but flashpoints for a couple of people in certain things.

Staff member

“ Because I didn't feel, I was getting very angry with her, and you know I was getting frustrated, and I was getting angry. So when I came back, I felt so relaxed.

Unpaid carer in Aberdeen

- 2.43** It is clear that the Awards had many indirect benefits for the people who received them. A relatively small amount of money spent on improving a person's physical environment or helping them to manage tasks for themselves can have impacts on emotional well-being, quality of life, independence and other support needs. It can prevent physical problems such as falls or enhance independence and as a result prevent or delay the need for a stay in hospital or move to a care home.

Did the impacts last?

- 2.44** For the vast majority of people, the impact from the Award has lasted for a long time. Almost all of the people who got Awards (96%) said that the Award made a difference to them straight away. But importantly, nine out of ten (89%) said that it would still make a difference six months to a year later.
- 2.45** For people who used the Award to buy something (like a new washing machine, walking frame, TV or bed) this item continues to make a difference to their daily lives. The impact on their level of comfort, independence, safety or stress is ongoing.
- 2.46** Those who spent their Award on a trip, a break or a special event, said the photos and memories are still being looked at and talked about. It is an ongoing topic of conversation, a shared memory, a story to tell others, with photos to look back on. For some, the Award contributed to a very personal and special memory, like the man who went to visit his brother in Canada for the last time, or the unpaid carer who took her mother for a longed-for break in Dundee (which was a special place in her past).



Mum has now died, but the trip to Dundee ... I've got all the memories, and I've got those memories of the last time that we spent, was such a wonderful time with Lucy as well...

Unpaid carer in Aberdeen



I have got very fond memories of my trip with my sister and my mum, and mum has still got some of it there, you know, although it diminishes, but she's still got some of it there, but we've got the photographs and stuff like that so yes we can reminisce.

Unpaid carer in Aberdeen

- 2.47** People who had spent their Award on practical help (such as garden work or house improvements) were still benefiting when we spoke to them, often many months later from the improvements to their environment. Day to day life was made easier and/or time and energy was freed up to spend socially.
- 2.48** For example, an unpaid carer in Lochaber who used her Award to pay for respite care for her mum so she could take her children to a concert now says she would do this again. She experienced benefits to her relationship with her children and it allowed her to try out respite and find that her mum enjoyed it too.

“ We still chat about it, the kids say, oh remember when we were away, you know we had dinner at the Hard Rock Café wasn't that so nice, and that sort of thing you know, flick through the photos on the phone.

Unpaid carer in Lochaber

“ I think we would do it again, she was quite settled cos that's her second time there, the dry run time obviously we were still local so we weren't far away at all if she didn't like it but you know we had to be sure for the second time, going away, you know, overnight, that she was going to be fine. it worked for us and she did enjoy the respite, you know.

Unpaid carer in Lochaber

Do the Awards affect other people?

2.49 The impacts of the Award often had effects on immediate family beyond the unpaid carer and person with dementia. Most often this 'knock-on' impact was in relation to stress levels and family relationships.

2.50 Adult children were relieved to see a decrease in stress levels where one parent was caring for another. People caring for a parent commented that their own partner or children seemed less worried about how they were coping with their caring role. An unpaid carer who used the Award for a break commented that, because her sister cared for their mum while she was away, her sister's understanding of her daily caring role had increased and this had improved the relationship between the two sisters.

“ I'm sure it helped my kids. They were getting so worried about me. And it was when we came back, and maybe because I looked so well, you know after not looking so well.

Unpaid carer in Aberdeen

“ It made my sister realise what we were doing... the showering of her and the changing of beds and there's quite a lot involved in caring for somebody, plus you know she couldn't go anywhere either, so it was an eye-opener to see what a carer's life is like.

Unpaid carer in Lochaber



Well, it probably helped my son and daughter as well because they had tried to help me with the garden. But they both have large gardens and everything of their own and family so they really don't have a lot of time and they have jobs so they don't have time really...it relieved them a bit and gave them a bit more time to help me with my husband.

Unpaid carer in Angus

Linking with other forms of support

2.51 The Life Changes Trust chose to involve local organisations to administer the Award because they have a good knowledge and understanding of support and services that are available locally. The lead organisations (Care and Repair) were also involved in another project, called the Dementia Enablement Project⁵, which aimed to help people living with dementia to stay in their own homes for as long as possible. The Dementia Enablement Project did this by providing equipment to keep the home safe or to help the person with dementia manage daily routines (e.g. grab rails in bathrooms, special clocks, nightlights). The Dementia Enablement Project also provided a local Care and Repair handyman service.

2.52 It was intended that the Dementia Enablement Project and the Individual Awards Scheme would refer people between them. This did happen in around a third of cases⁶, because the local organisations delivering both projects were able to make the connection between the two, perhaps helping people to use their Individual Award to buy a needed item and then helping them to access the handyman service for installation.



We did a TV for a gentleman, his eyesight was also affected, so we put a TV and a shelving up and all the rest of it. He bought the TV, and then Care and Repair installed the shelving and all the bits and pieces.

Staff member

2.53 Staff told us about referring people between the Individual Awards Scheme and the Dementia Enablement Project or supporting people to access both. Some staff supporting people to apply for an Individual Award arranged for the Care and Repair handyman to carry out a home safety visit and provide equipment or adaptations to make their home safer or easier for them to live

⁶ In total, 200 applicants were referred by Care and Repair Dementia Enablement Projects to the IAS. More than half of these were in Angus, which was the only project area to note they referred applicants to Dementia Enablement Projects as well.

in. For example, one lady whose hall carpet had been cut up the middle by a plumber and was 'downright dangerous' was helped to choose and pay for a new carpet with an Individual Award and staff arranged for the Dementia Enablement Officer to move her furniture and put it back again after the carpet had been fitted.

2.54 In some cases, the Individual Awards Scheme made local services aware of families who were not already aware of them and/or accessing their services. This meant that these people could be made aware of the Dementia Enablement project and supported to access this service, providing additional benefits and support for people with dementia and unpaid carers.

“ There was probably only a handful through the Scheme that we hadn't had in the enablement service. And once I'd met them, we put a referral through for the enablement service as well.

Staff member

2.55 We asked people whether the experience of applying for an Individual Award had helped them to find out about other kinds of support that they hadn't known about before. Some told us they had not previously known about their local Care and Repair team or Dementia Enablement Service and had now received help with other things, such as special clocks, nightlights, handrails and other adaptations.

2.56 Others had contacted a new organisation or type of support (for example, to apply for welfare benefits) through the support they received in applying for the Award.

“ Once you were involved with them, things started to come. Care and Repair. If you needed small repairs, you could phone them up and ...the tap in the kitchen was dripping and dripping and dripping away.

Staff member

“ Up until that point I hadn't realised that I could get a carers allowance or that I could get reduced council tax, so it was Angus Carers they were wonderful for that sort of information, and helping me to process all that ... and also there was another Award as well we got.

Unpaid carer in Angus

“

Once a month I go to a carers meeting, just myself, my hubby stays here and then once a month we both go to another dementia, Alzheimer's meeting in the local church hall, so we just feel like there's so much help it's brilliant.

Unpaid carer in Angus

Emotional well-being

Emotional wellbeing is a key benefit of the Award Scheme: many people experienced reduced levels of stress, anxiety, worry, and exhaustion. They spoke of positive effects on calmness and relaxation and 'knock-on' impacts on the quality of family time and relationships. For carers a small additional amount of money can provide an opportunity for a break from their caring role. This can support other interventions such as the Carers Allowance which is designed to give carers extra financial help.

Physical well-being

Physical wellbeing impacts were numerous and varied, but almost always had knock-on impacts on emotional wellbeing, through reducing pain or worry or increasing access to positive physical experiences such as time outdoors. Physical wellbeing and increased ability to undertake activity links to other policy areas, such as Scotland's National Walking Strategy which highlights the many benefits of physical activity (including reducing risk of disease progression for many illnesses and risk of depression, dementia and Alzheimer's), better psychological wellbeing, self-perception and self-esteem, mood and sleep quality, and reduced levels of anxiety and fatigue.

Connection and interaction

Memory is really important to people with dementia and unpaid carers. As the disease progresses older memories become more prominent and important than recent ones. The opportunity to reconnect with these memories brings great emotional benefit and new things to talk about, improving social interaction. Technology that helps people to stay connected with family, carers and the world around them has similar impacts on emotional wellbeing and social interaction.

A Connected Scotland, emphasises that reducing social isolation and loneliness has physical as well as mental well-being impacts. Increased independence, self-sufficiency and social inclusion can have benefits for mobility and muscle strength, decreased risk of falls and better overall quality of life.

Financial empowerment

The financial 'empowerment' that the Award represented for some people who received it was very important. Many people used their Award to do or buy something that they would not otherwise have afforded or felt they could justify. The freedom to decide for themselves what would make a difference to them was really important. Again, there were knock-on benefits for emotional wellbeing (relief, a little bit of financial freedom, stress reduction), social inclusion and other impacts.

Prevention

As well as the direct benefits people experienced through having this Award, there is some evidence of indirect benefits in the form of delaying or avoiding a need for more costly support. Practical help with jobs around the house or garden improved people's home environments and as a result often had impacts on emotional wellbeing, relationships and social inclusion. Importantly, this kind of help can support independence and quality of day-to-day life for people with dementia and unpaid carers, achieving a big difference with a small change. It can contribute towards delay in the necessity for more support or even help people to stay in their own homes for longer and can be viewed as a form of preventative spend.

The Age, Home and Community strategy also notes how home and garden improvements can impact on the need for more costly interventions by enabling people to live independently at home, preventing falls, improving quality of life and avoiding hospital admissions or a move to a care home. They can also help carers, by reducing the risk of injury and improving physical and mental health.

Long-lasting

The benefits of the Award, for most were lasting. Where the Award was used to purchase an item that promoted social inclusion, physical or emotional wellbeing, this continues to be the case. Where the Award was used to create or revive memories, these are still being discussed and bringing joy. Where the Award was used to do something new, it has improved confidence to repeat this experience.

Far-reaching

The Award often had impacts beyond the person who received it. Wider family and professional carers were relieved of worry or difficulty in supporting the person with dementia or the carer. Family relationships were often positively affected through reduction of stress or creating more time for family.

Connecting to other support

There is evidence of people being referred between the Individual Award Scheme and the Dementia Enablement Project and getting more help as a result. There is also evidence of people finding out about and using other support that they did not previously know about through their involvement in receiving an Individual Award.

3. What we learned about supporting people affected by dementia

- 3.1** Like the pilot scheme, it is clear from the evidence we have gathered that:
- a small amount of money can have significant, long-lasting and far-reaching impacts
 - one type of impact often leads to other, or several other positive changes
 - an approach like this can connect families to services they were not previously aware of
 - although it was beyond the scope of this evaluation to quantify it, it is clear that the impacts of an Award can contribute to prevention or delay of a need for more costly support
 - people need time, support and encouragement to identify what is important to them, but can be trusted to know.
- 3.2** Building on the findings of the pilot project, we learned some additional lessons that will be useful for helping to design grant schemes and wider Self-directed Support approaches to support people with dementia and unpaid carers in future.

What did people think of the Individual Awards Scheme?

- 3.3** Everyone we spoke to was very positive about the Individual Awards Scheme. The people who received Awards had all found it easy to do the things they needed to do, such as filling in an application form and thinking about what would make a difference to them. This was mainly due to being supported by someone from the local Care and Repair team or another organisation (such as Alzheimer Scotland) to help them. The support involved:
- Coming out to the person's home to explain the Individual Awards Scheme
 - Reassuring the person that they were eligible to apply and that they could apply for anything that would make a difference to them
 - Helping the person to think about the sort of thing that they might consider spending the Award on
 - Helping them to complete the application form
 - If it was needed, offering support with spending the Award once they received it.
- 3.4** The Scheme was funded by the Life Changes Trust and it was delivered by Care and Repair teams and other local organisations in each area. We found that

this approach made a difference to how people who received Awards felt about the experience. Being told about the Scheme face to face, often by someone they already knew, made thinking about what to apply for feel easier. Talking to someone who already understood some of their needs and difficulties and could make some suggestions about the sort of things they could apply for was helpful.

- 3.5 In this way, people with dementia and unpaid carers could really feel fully involved in the decisions and make the most of the opportunity to spend some money on something that would make a difference to their lives.
- 3.6 This approach also provided reassurance to people that they were entitled to receive this Award and that they would not be using money that someone 'more deserving' could have.
- 3.7 This Scheme allowed up to a year for people to spend the money they were awarded. The pilot scheme had a timeframe of only 2 months. It was clear that the longer timescale was helpful, allowing time to think and to re-think if circumstances changed, time to plan and time to access support to spend the money if needed.
- 3.8 For all these reasons, everyone we spoke to had found the experience extremely positive. Most were delighted to receive a little bit of help for something that they could choose themselves and in a way that felt dignified, respectful and supportive. All had found the application process very easy and this reduced worry and stress and encouraged them to apply.

“ I didn't feel like I was begging for charity or anything like that...They were so solicitous, explaining what it was for and... it was just an overall nice experience.

Unpaid carer in Aberdeen

“ I just thought well, we had to work for everything we ever had, no-one's handed anything to us before like that and it was just wonderful.

Unpaid carer in Angus

Feeling in control

- 3.9 The people we spoke to valued the flexibility of the Award Scheme. They felt they could genuinely spend the money on whatever would make a difference to them. Several were reassured that they could change their minds if circumstances changed. However, many needed support and reassurance about these things, which we discuss in the following sections.

3.10 For many people with dementia and unpaid carers, it is rare to be offered financial support without strings and or limits on what it can be spent on. Usually, any extra money or benefits have very specific criteria. Often there are also strict conditions about what any such money can and cannot be spent on. Most of the people we spoke to found the flexibility of this Award refreshing. For many, it felt ‘too good to be true’ and they looked for reassurance that they really could spend the money on whatever would make the most difference to them.

3.11 With this reassurance, most felt able to really think about what they needed either to help them on a daily basis or to improve how they felt about their situation. This meant a great deal to the people who received Awards.

“ I mean people have different circumstances and again it would be what would be most important and what the people themselves require, what they themselves decide you know, like us what we decided was important to us.

Unpaid carer in Angus

“ The good thing about it is they don’t put a limit on what you could actually get with it as long as you get something that would benefit you. Nobody said you have to buy such and such...

Unpaid carer in Lochaber

3.12 For some people, circumstances changed after they had applied for the Award⁷. These people really appreciated the flexibility to change their minds about what to spend the money on.

“ My knees are bad and I need knee replacements which I’m waiting for and earlier this year my Mum broke her hip, and she was just 5 weeks into it when my Dad broke his hip so it’s just been a terrible year. So I thought ‘right, I haven’t been out in a long time, I’ve been stuck in my bedroom so I’ll have a new wardrobe to cheer me up’.

Unpaid carer in Aberdeen

⁷ Partner Monitoring Forms note that change of use of the Award was rare, happening in 6% of Awards. In most cases this was due to illness or changes in the health of the person receiving the Award or carer.

The importance of relationships and trust

3.13 Relationships are really important when supporting people affected by dementia. We heard that people found it very confusing to deal with all the different systems, organisations and forms usually involved in getting financial assistance or services. People with dementia and unpaid carers can miss out on help because they are not aware of it, do not think they will be entitled to it or because the process of getting it is complicated.

3.14 The Individual Awards Scheme was delivered mainly by staff in the local organisations visiting people in their homes to tell them about it and help them to apply. Many of the people we spoke to would not have applied without this support: they would not have believed they would be eligible or would have assumed it would be a complicated process.

“ I think a lot of people’s experience is that everything comes with criteria or restrictions and you know, limits and to suddenly be told well no, actually this really is for whatever you need..

Staff member

“ People, because they’ve never seen something like this before, and kind of expect there to be maybe a catch or something somewhere, were still thinking ‘maybe, I shouldn’t spend it on this, maybe that’s a bit frivolous or I don’t really need that, so it should be for something ‘important’.

Staff member

3.15 Staff explained that people needed reassurance that this was ‘real’ and not ‘too good to be true’. People initially struggled to understand that this was different from other grant schemes they might have come across before and that they didn’t need to justify their need for something, rather just be able to say what was important or would make a difference to them. Some also needed support to overcome their concerns that, by applying, they would be ‘using up’ an Award that someone else might need more than they did.

“ You know, so you kind of had to explain that, you’re not taking money from anyone else. It’s there for you to use in any way that you would like if it’s going to make anything better for you, or to get any enjoyment out of it.

Staff member

3.16 Having an established relationship was helpful in providing this reassurance and trust. It was also valuable in the process of developing ideas and supporting people to identify things that could make a difference to their lives. Some people worried about being given money ‘for nothing’ and needed encouragement that they were ‘deserving’. This type of reassurance through a trusted relationship was crucial in encouraging people to apply and to truly choose something that would make a difference to them. One participant said that because the information they received included a logo they were familiar with, they knew could trust it.

“ They’ve got a card with my photograph on it and my contact number on it, and that was one of the things that made a difference. ... it was a bit stressful for those people because, I think getting that kind of money as well, they just needed that stability.

Staff member

3.17 Applying with the support and encouragement of someone who knew them well was sometimes helpful in supporting people to think about what would make a difference to them. Staff made suggestions based on their knowledge of the difficulties that people were experiencing or linked to the things that mattered to them. Sharing examples of ways in which other people had spent the Award helped to reassure concerns about what was ‘legitimate’.

“ It’s hard to say because I wouldn’t have been aware of it if it hadn’t been for Lucy’s involvement but even if I had been and hadn’t her involvement then I probably wouldn’t have applied, you know what I mean. It was just because she was pointing out our need that I applied.

Unpaid carer in Aberdeen

“ I was out doing a home visit with and one lady, she expressed a concern about safety on her stairs because of the state of her hall carpet and I was like, well you know what? I can maybe just help you out there - so that was really good.

Staff member

3.18 Some people told us what a big difference this kind of personal, face to face support meant to them. Caring or living with dementia can be very lonely and a supportive, trusted helping hand can have a significant impact on how people feel about their situation.

3.19 The Individual Awards Scheme did also help to establish a few new relationships between people affected by dementia and local services⁸. In all three areas, ‘a few’ or ‘a handful’ of those applying for Awards were new clients to the partner organisations, who will now be aware of them and able to access their services. Having met staff face to face, they are more likely to feel comfortable phoning for help with something else in future and, although there were only a few people in this category, staff did ensure that they made the links to other services for them.

“ It’s establishing relationships with people which can then feedback into our main projects. So, the feedback we’re getting back from the Awards is feeding back into the main dementia projects as well as establishing the relationship, formulating in people’s minds not just the Awards but the whole dementia project.

Staff member

Support really helps

3.20 Our evidence suggests that the support with applications helped to ensure that people got the maximum benefit from the Individual Awards Scheme. Using their local knowledge, staff ensured that people knew about the Awards, reassured people that they could apply and helped them with the process of applying for the Award. This meant that people affected by dementia had very positive experiences of applying for the Award, got the maximum benefit from it and were fully involved in deciding what to apply for and how to spend the money. In short, they were supported to be in control of the process and the decisions.

3.21 In all three areas, help with completing the form was offered as a matter of course and where the offer was taken up, staff tended to do this face-to-face. The different areas recorded information about this in slightly different ways, but it can be seen from the information in Appendix 2 that the level of support needed and given varied by area⁹. In many cases, this was part of an ongoing relationship of offering support and advice and in a few cases in each area, it extended to help with obtaining costs or estimates.

“ Without her talking to us, explaining to us we would never have known anything about it, would never have dreamt of applying for anything to help us with things like that, household things

⁸ 3% said that they got access to new or additional support as a result of their Award.

⁹ One third (33%) required/received support in Aberdeen, over half (55%) in Lochaber and nine in ten (90%) in Angus.

“ I spoke to Pam and she said ‘yes, you can have what you want’ and then she went through with me the reasons, how it might help me, what it had done for me, she went through that bit with me to save me doing it myself...it was a great help.

Unpaid carer in Lochaber

3.22 Support with spending the money once Awarded was not often needed, although people had a range of follow up questions for example about receipts, if money was left over, not having spent the money and so on. Again, reassurance was the main support needed. This tended to be around changing what the money was to be spent on (usually because of changed circumstances, like no longer being well enough to go on a planned break) or having money left over. In these circumstances, people expected they would have to return the money and needed reassurance that they could take their time to spend it or spend it on something else that was important to them.

“ It was really, really good, it was it was lovely, it went really smoothly, we were just encouraged to enjoy the money and just keep the receipts, but there was no pressure there was no anything, it was very easy to apply for, I didn’t feel guilty that I was doing anything untoward or anything, you know.

Unpaid carer in Lochaber

“ She told me what I could apply for, what I could use it for ...she looked after all that for me. I wouldn’t even remember what I had signed.

Unpaid carer in Aberdeen

3.23 The learning we have described in this section about supporting people affected by dementia reinforces much of the learning from the implementation of Self-directed Support when it is working well. In particular, the very positive outcomes that can occur when people:

- Know the resources that are available to them
- Have the right support to help them think and plan about what they want to achieve
- Are able to keep an absolute focus on their personal outcomes and not on how resources are used.

Simplicity

We learned that keeping the application process simple and making it feel easy to apply were really important in encouraging people with dementia and unpaid carers to apply. A complicated application form or process is off-putting to people whose lives can be already complicated enough. Keeping things simple and providing support helped people to feel in control.

Flexibility

The flexibility of this Award was really important for helping people to feel in control of the process. Once they understood that they could really spend the money on anything that would make a difference to them, they felt trusted and able to take control and identify a real need, choosing things that reflected their specific circumstances, rather than simply what they felt they might be 'allowed'.

Trust

We learned that trust is important in encouraging people to apply for this kind of help. Support and reassurance delivered face to face by someone they already knew and who understands their situation and needs was crucial to trust in the Scheme and to feeling trusted to identify what is important to them. Without this most would be unlikely to access this kind of Award.

A personal approach

The personal support provided was necessary for practical help with things like completing the application form. It also helped people to feel in control and reassured about the process and the purpose of the Award.

Control

We learned that many of the essential elements that make an awards scheme like this work well, like focussing on freedom, dignity, choice, control, flexibility and trusting in people, are the same as the essential elements necessary to really unlock the potential of people directing their own support more widely.

4. Lessons for the future

- 4.1 A relatively small amount of money, with the person able to choose how to spend it, can have a big impact for people with dementia and unpaid carers. Often the impact on well-being is enhanced by the person feeling valued and worthy of investment. This is additional to the direct benefit from using the Award itself, which can be physical, emotional, practical or social. There are important lessons for the design of future grant schemes and public policy more widely, in order to support people with dementia and unpaid carers to live the best life they can. This section describes what we have learned.
- 4.2 Whatever the immediate or obvious impact, generally there are additional impacts, often unanticipated, particularly on well-being. These positive effects often extend beyond the person who receives the help to wider family or carers. The impacts usually having an ongoing benefit for many months after the initial spend. So, a small amount of money spent can help reduce or delay the need for support in a wide variety of ways and for more people than the recipient. Policy on self-directed forms of support should reflect the links to and benefits for delivery of other policy areas (such as, housing, mental health, social isolation and loneliness).
- 4.3 It can be very straightforward and relatively inexpensive to meet people's needs. A small amount of money and help to choose how to spend it can save a lot by helping to avoid or delay a need for other, more expensive types of support. This can provide benefits that help people to stay in their own home for longer, reducing the need for more costly support. It can be viewed as a preventative spend. The unseen contribution that unpaid carers make to support people living with dementia at home can be seen clearly through the examples shared in this report. The Awards made a significant contribution to strengthening the resilience of some carers, enabling them to continue in their caring role. These are important findings for Health and Social Care Partnerships when considering allocation of resources and implementation of Self-Directed Support provision.
- 4.4 In planning the delivery of this kind of Award, it is important to recognise the value of face-to-face provision of information and support by a known person or organisation. People with dementia and unpaid carers need support to think about what they need and to complete application forms. Some also need some ongoing support or reassurance in relation to spending the money. The person providing this support should be someone who knows about and can help people to access the other types of support available in the local area. This is an important finding for both statutory and third sector organisations

(as well as their funders) designing grant or support schemes for people with dementia and/or unpaid carers. Using 'grass roots' channels to communicate about a scheme and to support applications is vital and application processes need to be simple and straightforward.

- 4.5 A valuable additional benefit of this support is helping people to think about change and to test and try new things that they would not otherwise feel empowered to do. With or without an Award Scheme, this is an important type of support to provide and can have real and lasting benefits. Again, it relies on personal support and relationships, often with individual statutory or third sector organisations or workers.
- 4.6 Flexibility is very important to help people feel in control. The freedom to genuinely choose what will make the biggest difference to their own lives (instead of trying to meet specific eligibility criteria) helps people to feel confident and willing to apply and to optimise benefit from any grant available. If support is to be truly self-directed, it needs this flexibility. Grant programmes should recognise that people can identify what will make a difference to them. Those responsible for designing and delivering or administering self-directed types of support should keep any criteria broad-ranging and simple to understand so that they provide genuine freedom, control, dignity and choice.
- 4.7 The flexibility and time to change what the money is spent on if needed is also very important. Circumstances can change both for people with dementia and for unpaid carers. The ability to change a decision about what would make a difference to them means that they can still benefit from the support if this happens. Broad criteria and generous timescales will encourage freedom to decide and genuine choice.
- 4.8 This type of support is best delivered by local organisations. This is because they have connections to the other supports available locally and can help people to access these. Support should be designed to be delivered through, or in partnership with, the local organisations who have these connections and established relationships with many of the beneficiaries.
- 4.9 As well as the specific learning for the future that can be drawn from the delivery of any similar grant, there are links and learning for public policy more generally, and in particular to the legislation, policy and practice developed for Self-Directed Support and support for carers. Feeling in control and having flexibility; the importance of relationships and trust in developing and implementing plans about what matters to people; and accessing support that is tailored to individuals and their circumstances are all vital for the success of any Award scheme and to in successfully delivering personalised social care support for people living with dementia and unpaid carers in Scotland.

5. Acknowledgments

The Lines Between would especially like to thank all the people with dementia and unpaid carers who contributed to this work.

We would also like to thank In Control Scotland, The Care and Repair teams in Aberdeen, Lochaber and Angus and their local partners: Alzheimer Scotland and Angus Carers in Angus, Connecting Carers, Voluntary Action Lochaber and Care Lochaber in Lochaber and Age Scotland and In Control Scotland in Aberdeen.

6. Appendix 1 Methodology

We looked at a lot of information and talked to a wide range of people to find out how the Individual Awards Scheme has worked in the three areas (Aberdeen, Locharter and Angus). Our approach to the research is summarised below.

We spoke to...

47 carers

28 people with dementia

18 staff

We looked at...

application forms and feedback from people who received Awards

information about those who received Awards

Workshop and round table sessions with In Control Scotland and the organisations administering the Awards



And we produced...

a range of personal stories from those who received Awards

a report based on our findings

7. Appendix 2 Some facts and figures

Who applied for and received Awards?

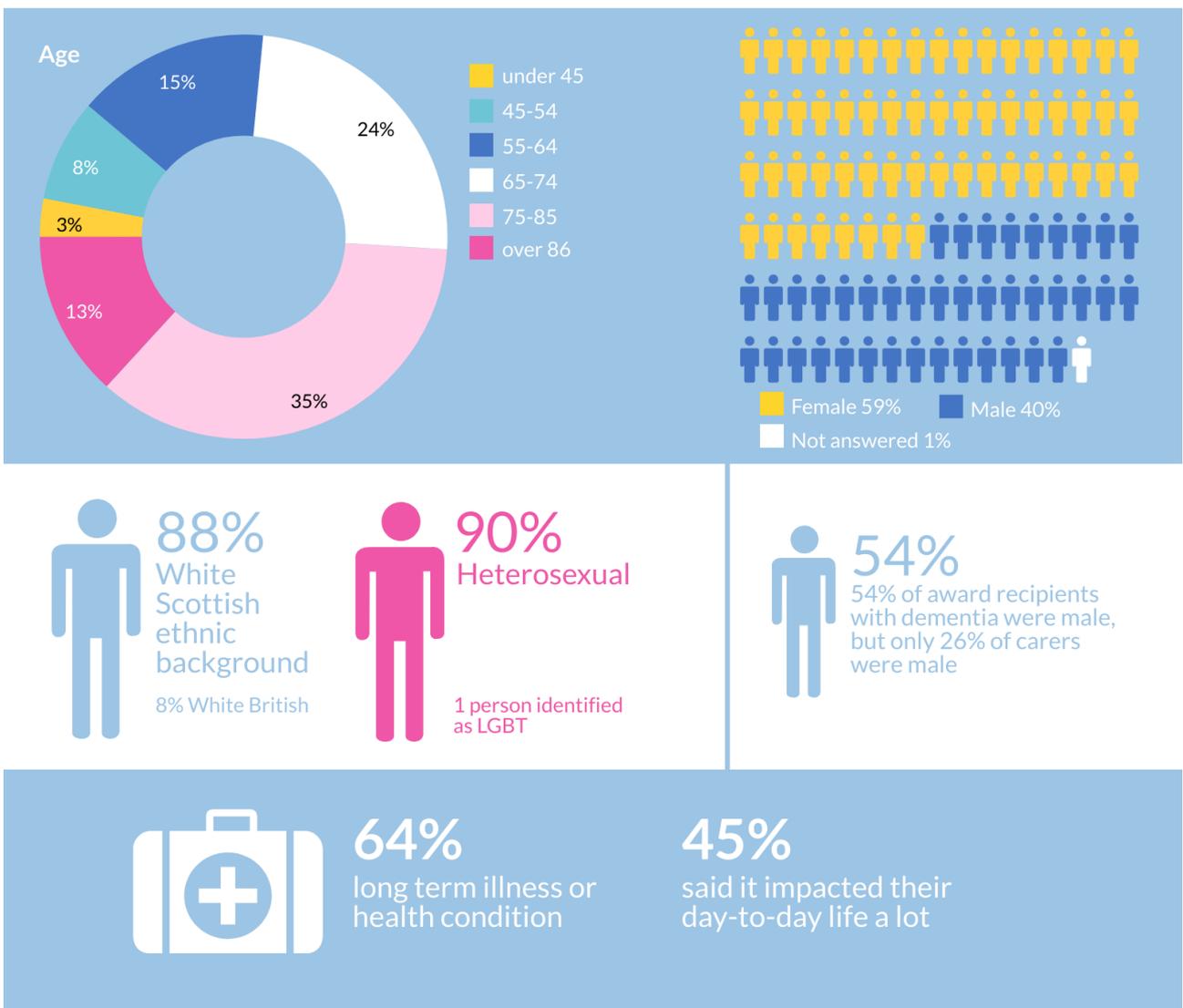
This information comes from analysing the equalities monitoring data, which was collected via Equalities Monitoring Forms (EMF). These were completed and returned anonymously by people who applied for Awards, so they cannot be linked to any of the other facts and figures.

The data in this report is based on the 411 forms that were sent on to The Lines Between, which represents 68% of Awards.

Characteristics of the people who received Awards are summarised in the graphic below:¹⁰

The most common age range was 75-85

More females received awards than males



¹⁰ Categories may not add to 100% as not everyone answered all questions on the Equalities Monitoring Forms.

Applications

A total of 608 applications were made to the Individual Awards Scheme¹¹. The highest number of applications were received in Aberdeen (309, equating to 51% of all applications), followed by Angus (214, 35%) and Lochaber (85, 14%).

Applications were evenly split between people with dementia (303 – 50%) and people caring for someone with dementia (305 – 50%). Just under one third of applications (187 or 31%) were identified as linked applications, with virtually all of these (181 – 97%) linking a person with dementia with their carer. That means that the person with dementia and their carer each applied for an Award.

The proportion of linked applications in each area varied. While 61% of applications in Lochaber were linked, there were 37% in Aberdeen and just 10% in Angus. This may be due to different interpretation of the application process by the organisations who were delivering the Individual Awards Scheme in each area.

This may also be due to the different nature of referrals in each area. In total, 200 applicants were referred by Care and Repair Dementia Enablement Projects to the IAS. More than half of these were in Angus (117 out of 200), which equates to 55% of applications in Angus. This is higher than the 17% in Aberdeen and 35% in Lochaber.

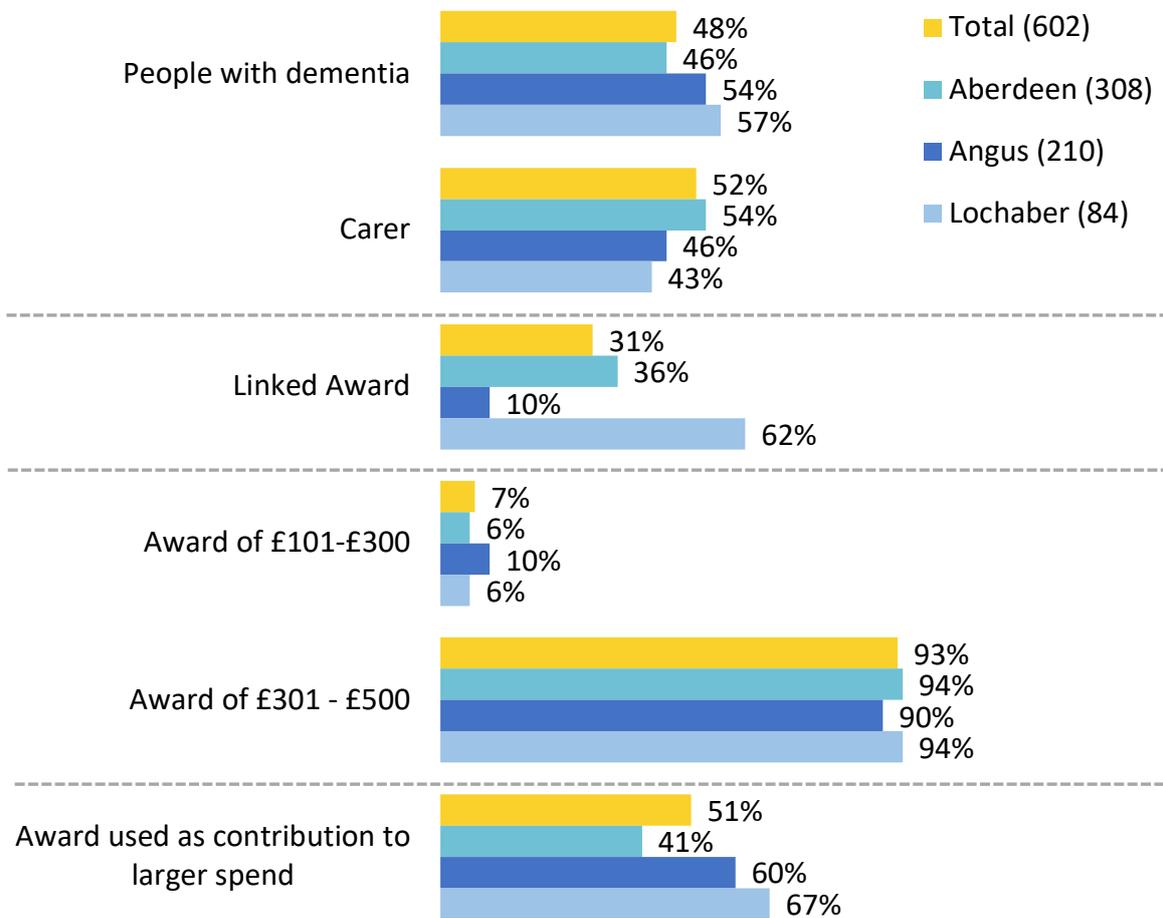
Awards

Graph 1 shows, at a total level and for each of the areas, the proportion of Awards given to carers and people with dementia. It also shows the proportion of linked Awards (where 2 people in the same household or family received Individual Awards), the size of the Award and whether the Award was used as a contribution to something costing more than £500.

¹¹ Data returns as follows: Aberdeen and Lochaber up to 30th November 2019, Angus up to 16th December 2019.

Graph 1: More information about Awards – % Total and by area

Source: Partner Monitoring Forms



The split of Awards was the same as that noted above for applications, with just over half being carers and just under half being people with dementia. This relatively equal split is evident in all three areas. However, a larger proportion of Awards in Aberdeen went to carers (54%), and conversely people with dementia made up a majority of Awards in Angus (54%) and Lochaber (57%). The clear difference in the proportion of linked Awards in each area remains evident, ranging from 10% in Angus to 62% in Lochaber.

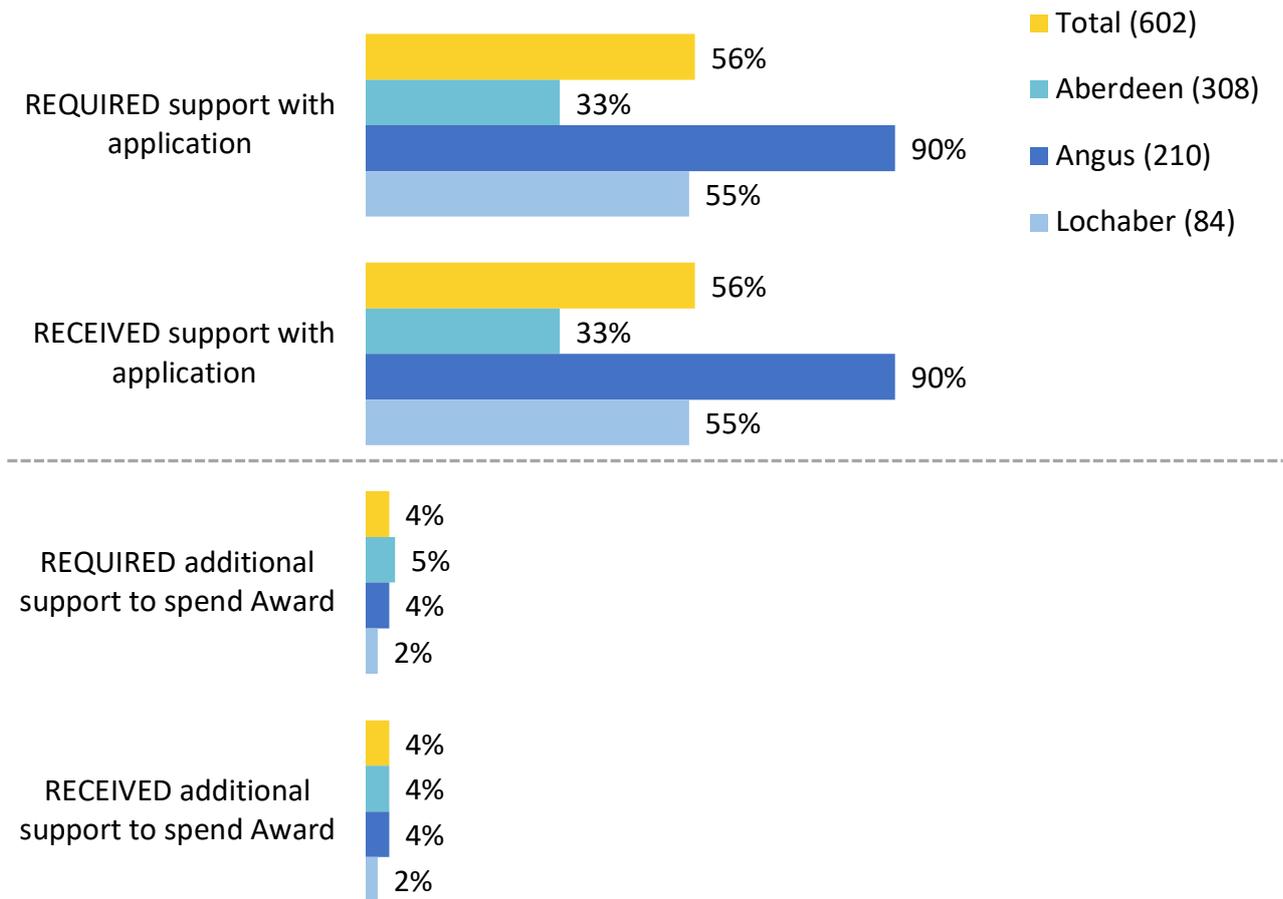
Fewer than one in ten Awards (7%) were for £300 or less, with the vast majority being for between £301 and £500. This was the case in every area. The average value of an Award was £467. The average value was reasonably similar across all areas but was slightly lower in Angus (£451 compared to £477 in Aberdeen and £473 in Lochaber). There was essentially no difference between the value of Awards given to carers and to people with dementia - £469 and £466 respectively.

Support to people applying for and receiving Awards

Graph 2 shows, at a total level and for each area, the levels of support provided to people applying for and receiving Awards.

Graph 2: The proportion requiring and receiving support with their Awards – % total and by area

Source: Partner Monitoring Forms



Overall, over half (56%) of applicants needed support to prepare or fill out their application form. This varied considerably by area, from 33% in Aberdeen to 55% in Lochaber and 90% in Angus. This likely reflects differences in the way the Scheme was administered in each area. The higher level in Angus might be because of the greater number of referrals by Dementia Enablement Projects. The majority of the applications in Angus were completed by the Care Support Worker. It is clear, however, that all those who required support received it.

There is no evidence of there being any difference between people with dementia and carers requiring or receiving support.

As shown in Graph 2, the number of people who needed additional support to spend their Award once they received it was very small, amounting to 25 people or 4% of all Awards. The vast majority of those who required support received it, with 2 people in Aberdeen refusing assistance.

Purpose of Awards

Awards were granted for a very wide range of purposes. Table 1 shows the number of Awards granted for each purpose across the Individual Awards Scheme, and the proportion of all Awards that each category represents.

Table 1: What Awards were used for

Source: Applications forms (607), shows only categories contributing to 2% or above.

Category	Number of Awards	% of all Awards
Any home renovation or garden related	199	33
- Garden	74	12
- Any home renovation	125	21
-- Home Repairs or Renovation	46	8
-- Redecorating	28	5
-- Flooring or Carpets	21	3
-- Bathroom Improvements / Adaptations	15	2
-- Heating	14	2
Any trips, breaks or outings	164	27
- Short / overnight / weekend break	69	11
- Holidays	58	10
- Outings / Day Trips	17	3
- Visiting friends or relatives	16	3
Any furniture or appliances	156	26
- Comfortable Chair / Sofa	33	5
- Information or Communications Technology	26	4
- TV / DVD	25	4
- Bed / Mattress / Bedding	19	3
- Food Preparation Equipment	10	2
- Housework Aids (other than laundry)	14	2
- Laundry Equipment	13	2
Other	88	14
Transport-Social	15	2
Other	12	2
Activities outwith the Home	10	2
Mobility or Sensory Aids	10	2

Across the whole Scheme, there were three overarching reasons for applying for an Award. Awards for home or garden purposes were most common, making up one third (33%) of all Awards. Garden was the most common single category across the Scheme (12% of all Awards). 27% of Awards were for different types of trips, breaks or outings. Within this, short overnight or weekend breaks (11%) were most common, followed by longer holidays (10%).

The third main reason for applying for Awards was to get or replace furniture or appliances. Specifically, 5% of Awards went towards chairs and sofas, 4% to technology such as computers or tablets, and 4% to TVs and DVDs. Beyond this, other categories represented 5% or less of all Awards.

The purpose of Awards varied across the three areas:

- In Aberdeen home and garden improvements were most common (33%), but Awards were also used for trips (29%).
- Home and garden improvements were also most common in Angus (36%), but this was driven by a higher level of garden related Awards (16% compared to 11% in Aberdeen and 6% in Angus). Trips were less common (21%).
- In Lochaber Awards were more likely to be used for furniture and appliances (33%) and trips (33%) than in the other two areas.

There were also differences by whether the Award was for a carer or a person with dementia:

- For carers, the most common reason was trips, which represented 33% of their applications (compared to 21% of people with dementia).
- Awards for people with dementia were most likely to be for home and garden improvements (36%, comprising 24% for home improvements and 12% for garden improvements). People with dementia were also more likely to use Awards for furniture and appliances (28% compared to 23% of carers).

Other specific differences between the two groups were small but included 7% of Awards for people with dementia being for chairs/sofas (compared to 4% of carer Awards) and 4% of Awards for carers being for transport for social reasons (compared to 1% of Awards for people with dementia).

Expected and actual impact

The application form asked applicants to describe how the Award would make a difference to their lives. For the purposes of analysis, The Lines Between reviewed all comments and coded these according to a list of options agreed with Life Changes Trust. These were:

- Access to support
- Empowerment
- Quality of life (practical)
- Social inclusion
- Wellbeing (emotional)

For some people, more than one of these options was relevant.

Across the Scheme as a whole, almost two thirds (63%) of applicants indicated on their application form that they expected that the Award would have a positive impact on their quality of life and just under half (48%) expected a positive impact to their emotional well-being. Around one in ten anticipated improved empowerment or social inclusion, and 1% cited access to support as an additional outcome.

Table 2 outlines the expected impacts by area and by the type of person applying. People receiving Awards in Angus were more likely to expect an impact on quality of life and less likely to expect an impact on emotional well-being. This is likely to reflect the slightly different profile of Awards in Angus, with fewer being for trips than the other two areas. Carers were more likely to expect a positive impact on their emotional well-being, but people with dementia were more likely to expect a difference to their practical quality of life.

Table 2: Expected impact of Awards – % Total, by area and by type of applicant

Source: Applications forms (607)

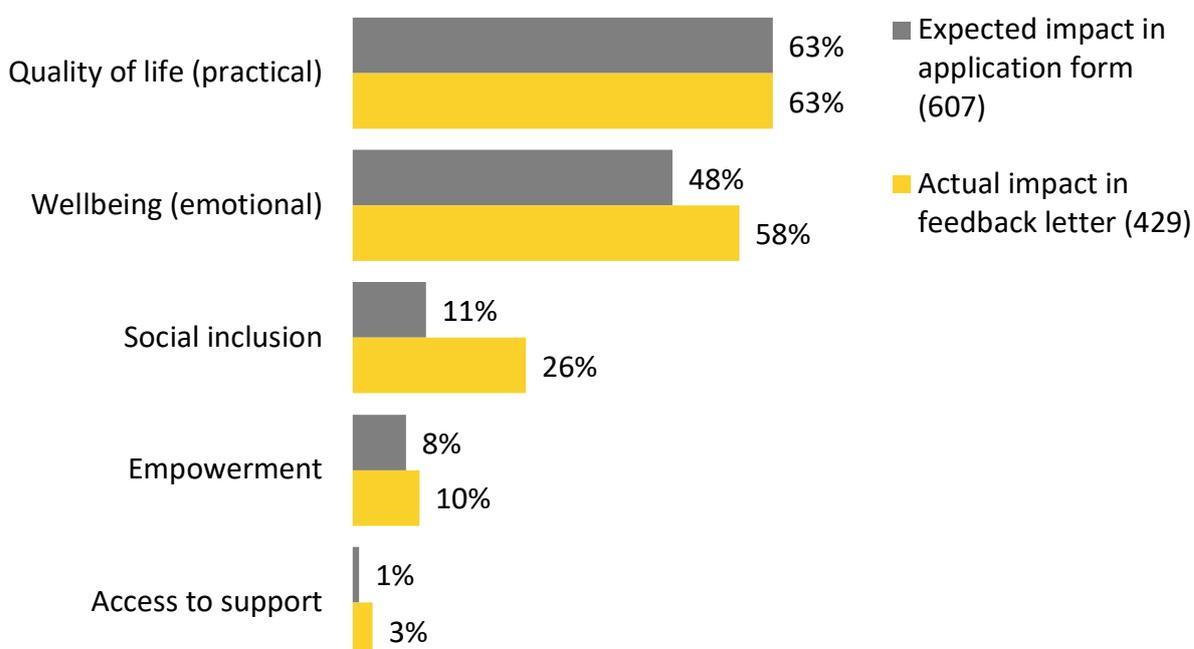
Expected Impact	Total (607)	Aberdeen (309)	Angus (213)	Lochaber (85)	Dementia (301)	Carer (305)
Quality of life (practical)	63	57	72	65	69	57
Wellbeing (emotional)	48	56	38	47	42	54
Social inclusion	11	11	9	19	11	12
Empowerment	8	10	6	7	9	8
Access to support	1	2	0	2	1	2

When they gave their feedback after they received their Award, people were asked to complete the sentence: 'It made a difference to me because...'. Again, their descriptions of the impact the Award were coded by The Lines Between and for consistency the same agreed list of options was used, and more than one could apply.

Graph 3 shows the proportion of people who expected each type of impact (as indicated on their application form) and how this compares to the proportion who feel they actually experienced that impact (as expressed in their feedback after they had the Award). It should be noted that the figures for actual impact are based on the total number of feedback letters received.

Graph 3: Expected impact of Award compared to actual impact (%) – Total

Source: Applications forms (607), Feedback letters (429)



The same proportion – 63% - expected a positive impact on their practical quality of life prior to the Award and experienced this as a result. This is understandable, as it is probably easier to anticipate the impact of a practical change (for example a riser chair).

Encouragingly, there is evidence that people felt the other less tangible impacts more than they expected. Almost two thirds (58%) of those returning feedback letters indicated the Award had impacted their emotional well-being (compared to 48% who had expected this), 26% felt more included (more than double the 11% who expected this) and 10% felt more empowered (compared to 8% who expected this).

Feedback letter

After people had received and spent their Award, they were asked to complete a feedback letter and return it to their local partner organisation: 429 were received by The Lines Between for analysis, which represents 71% of Awards.

In the feedback letter, people who had received an Award were asked if the Award made a difference to them straight away. Of the 385 people who gave a response to this question, virtually all - 96% - said it had, 2% said it had not and 2% were not sure.

There was the same high level of agreement in all three areas - 95% in Aberdeen, 95% in Angus and 100% in Lochaber. Similarly, 96% of carers and 96% of people with dementia agreed it had made an immediate difference. This clearly demonstrates the value of the Award.

People were asked if the Award might still make a difference in the next 6 months to one year. Of the 390 who answered this question, 89% said that it would, with strength of agreement very clear: 79% 'yes, definitely' and 10% 'probably will do'.

Nine out of 10 agreed in all three areas, though strength of agreement was notably higher in Angus. Overall 87% agreed in Aberdeen (78% 'yes, definitely') and 89% agreed in Lochaber (70% 'yes, definitely'), but in Angus 93% agreed, driven by the 84% who said 'yes, definitely'. There were similar high levels for carers (88%) and people with dementia (91%).

The feedback letter also asked people whether they would have done/bought what they did without the Award. As shown in Graph 4, half (49%) said that the Award had allowed them to do something that they would not otherwise have done. A further fifth indicated that they may still have done/bought what they did, and another fifth were unsure. Only one in ten indicated they would have definitely done/bought what they did regardless of having the Award.

Graph 4: Whether people would have done what they did without the Award (%)

Source: Feedback letters – all answering question (391)

