



Individual Awards Scheme Evaluation Report - A Summary

Conducted for:



Report Summary

The Awards

The Individual Awards 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.

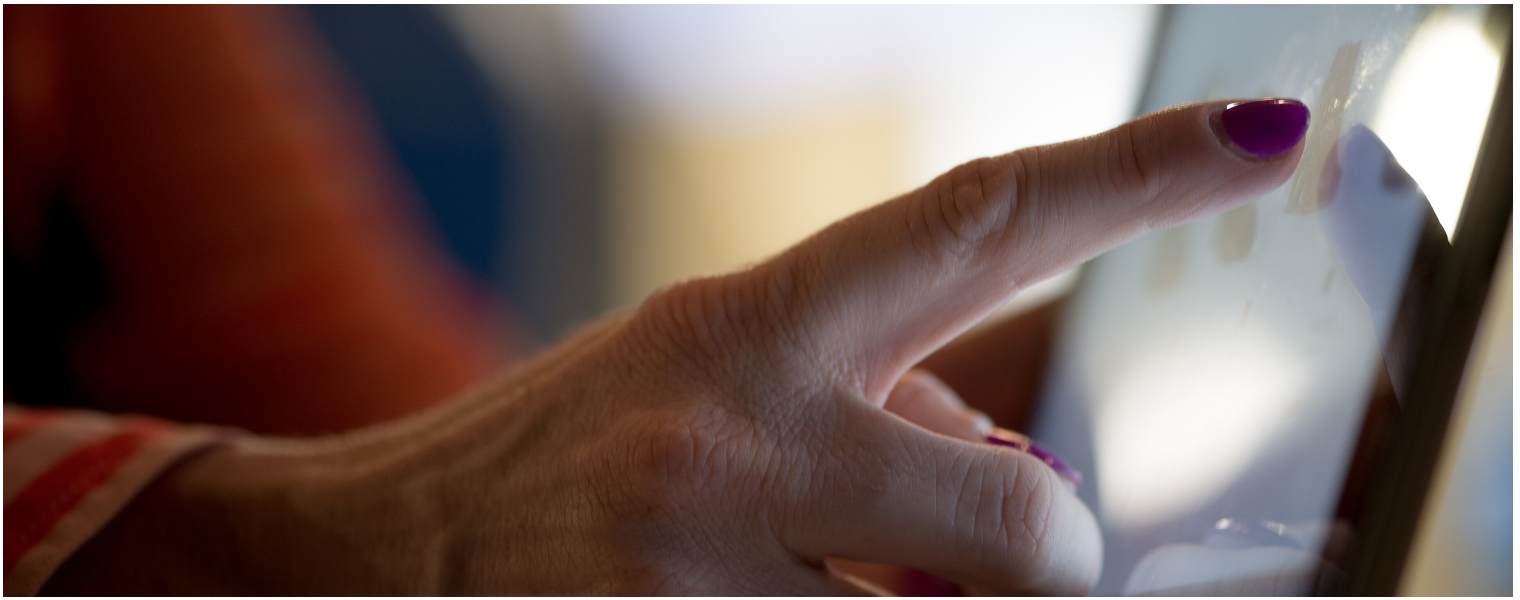
There are also links to public policy more generally and in particular, learning for policy and practice in the area of Self-directed Support and support for unpaid carers. To successfully deliver personalised social care support in Scotland for people living with dementia and unpaid carers in Scotland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

Stories

Here are some 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.

The ripple effects of the award for Anne and her family





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)

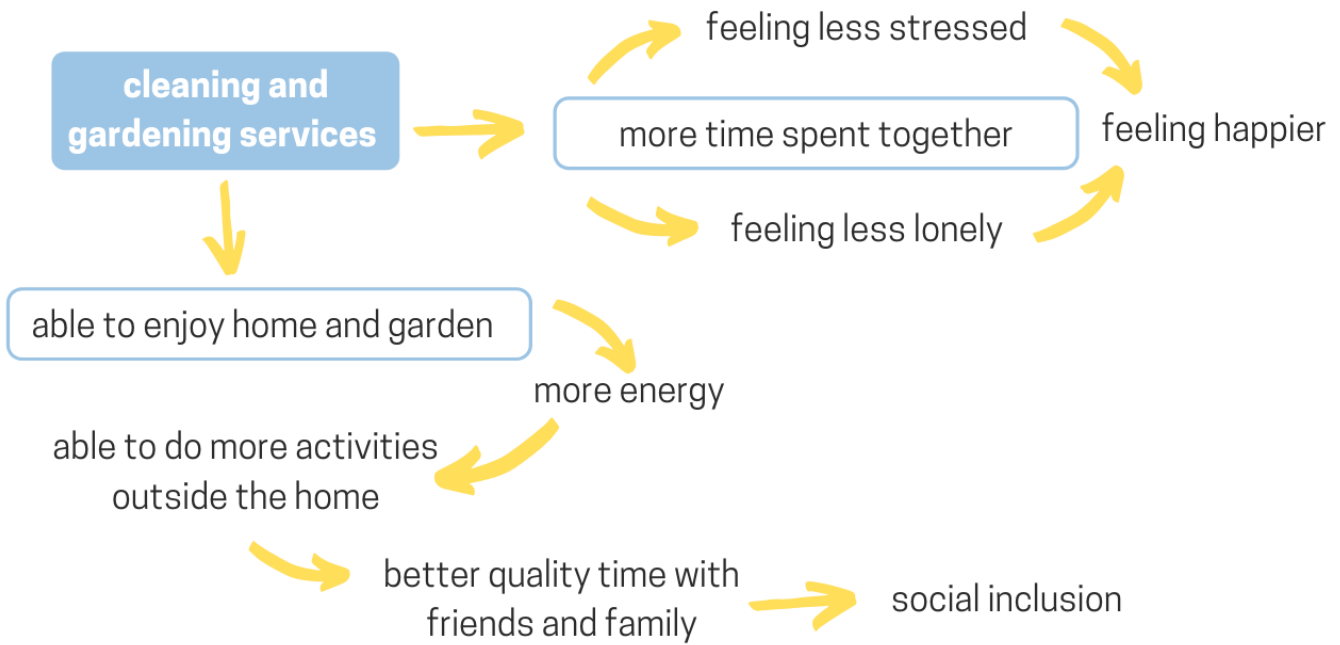
Help with the cleaning and gardening has had wider impacts than any of them expected. Bill feels less stressed, Lizzie is enjoying the extra social time and Cath has noticed her dad is less tired and more cheerful. As a result, they were all more confident about the couple’s ability to keep on coping 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





“

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.**”



“

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.



“

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

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

33%
spent their Awards on their home
or garden

8%
home repairs



5%
redecorating



3%
flooring or carpet



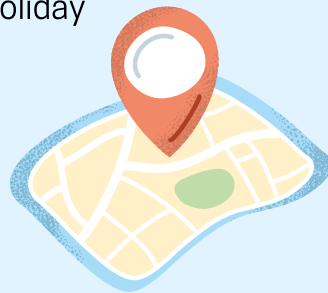
12%
garden

27%
spent their Awards on trips,
breaks or outings



11%
short overnight
trip or weekend
break

10%
holiday



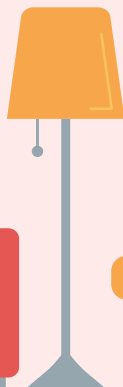
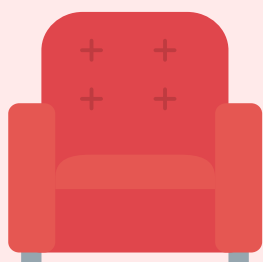
3%
outing or day trip

3%
visiting friends or family

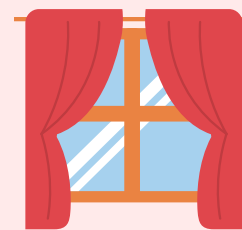


26%
spent their Awards on furniture
and appliances

5%
chair or sofa

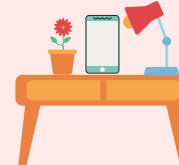


4%
TV or DVD



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.

★ 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.

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.

