

Putting Beneficiaries at the Heart of Funding

Introduction

The Life Changes Trust was established by the National Lottery Community Fund in April 2013 with a spend out endowment of £50 million. We have used that endowment to support and drive transformational improvement in the quality of life, wellbeing, empowerment and inclusion of three groups in Scotland: people living with dementia, unpaid carers of those with dementia and young people with care experience.

The main ways in which we do this are by:

- ▶ Investing directly in people and expanding the choices and opportunities available to them
- ▶ Investing in the work of public and third sector partners that champion their inclusion, leadership and rights

Listening to, amplifying and acting upon the voice of the people we're here for is woven into the fabric of the Trust. Over the past eight years, we have developed a deep understanding about what leads to significant and positive change in people's lives.

As we approach the end of the Trust, we are focused on leaving a positive legacy. In order to do that, it's important that we explain what we do and how we do it, as well as share insights into the impact of working in this way. This funding booklet is one in a series of four:

- ▶ Putting beneficiaries at the heart of funding
- ▶ Relationship-based funding
- ▶ Being a flexible funder
- ▶ Being a strategic funder

The Trust's approach

What does it actually mean for a funder to 'put beneficiaries first'?

For the Trust, it means giving consideration to who is in the room when important things are happening and decisions are being made. It means thinking beyond the distribution of money to consider everything that precedes a funding decision and everything that comes after it too. This includes how funders develop grant programmes, support applicants, assess applications, make funding decisions, deliver events, develop communications, share learning, recruit staff, procure services and much more.

The Trust also provides a supportive framework for funded organisations to meaningfully involve the people that they are there for. This includes being a flexible funder, delivering training, facilitating network events to share learning, offering consultancy support from Trust advisers, focusing on and valuing relationship-based practice, and more. We share specific learning around this in our 'Relationship-based Funding' booklet.

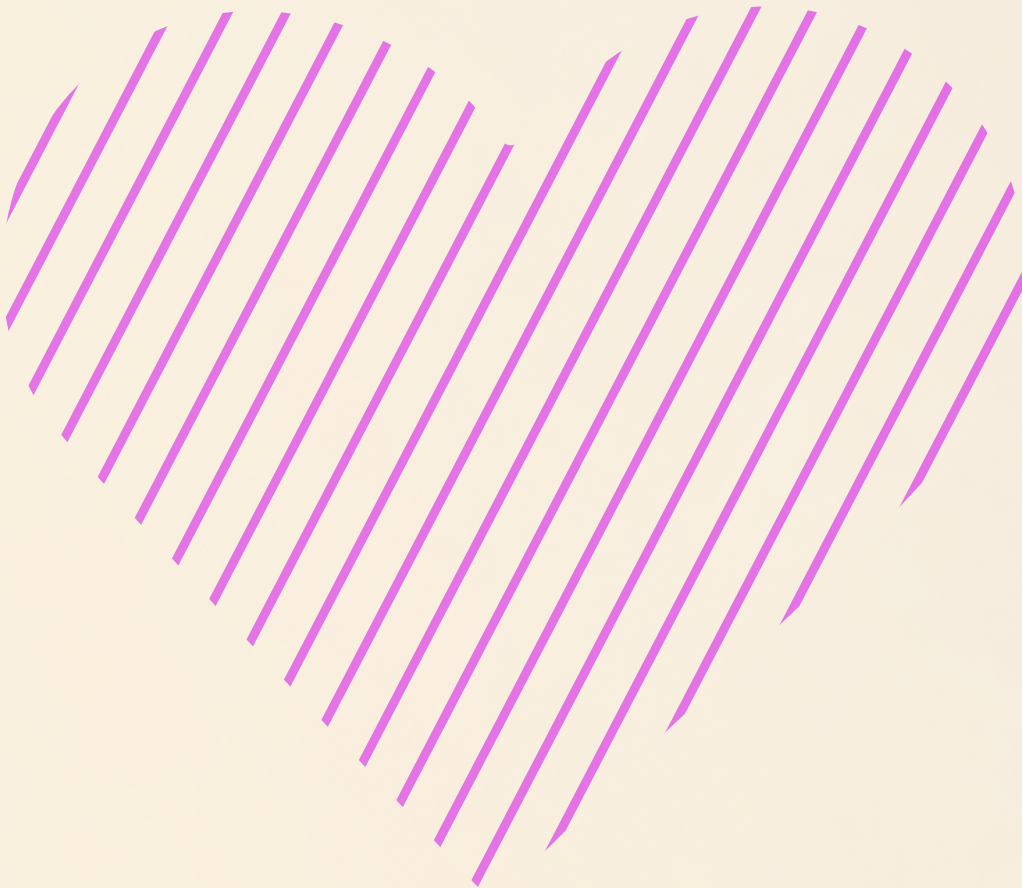
In terms of putting beneficiaries at the heart of any funding initiatives and activities, a variety of terms and labels are often associated with this way of working – including co-design, co-production, relationship-based practice, participatory grant-making, and person-centred funding.

The New Economics Foundation's description of co-production offers a very helpful starting point for funders who want to transfer power and fully involve people in their funding practice:

“Co-production is a relationship where professionals and citizens share power to design, plan, assess and deliver support together. It recognises that everyone has a vital contribution to make in order to improve quality of life for people and communities.”

In reality, no single label fully explains or encapsulates the complex and people-based approach taken by the Trust. Our approach has developed over time, and exploring different ideas and refining practice alongside people has been an important part of the process.

While we cannot offer funders a blueprint for how to ‘put beneficiaries first’, we can articulate five key touchstones for this way of working.



Key touchstones for funders putting beneficiaries first

1. Invest in positive relationships

Our relationships with people thread through everything that we do, and every staff member at the Trust understands the importance of those relationships. This work is professional and it is personal. It requires an investment in and from **staff**. The Trust commits time and resource to nurture reciprocal relationships because we know that they blossom with consistency, care and attention.

Investment in relationships can take many different forms, from providing professional training to supporting all of the things that are often the first to be questioned when budgets are tight in an organisation. Sometimes it's about remembering a birthday, making time to have a cup of tea with someone, providing references, or celebrating achievements and positive news with each other. Other times it's about supporting the personal development of volunteers, investing in staff training around safeguarding, or having honest conversations around remuneration.

Example: Creating the right environment is an important part of relationship building. The Trust works alongside people in spaces that are comfortable and welcoming. Those spaces have always reflected and supported strong relationships. They are places where people stop in for a chat, where people's creative outputs are on full display and where co-production flourishes. These spaces reinforce the feeling that we are all a part of the Life Changes Trust.

2. Stay focused on shared values

Developing, nurturing and staying focused on shared values is central to the work we do alongside beneficiaries.

For the Trust, relationships often begin with exploration. Whether it is forming an Advisory Group, developing a funding initiative or hosting a series of events, we believe it's important to begin with an understanding about - and an appreciation of - who is involved, and what our shared values and goals are. From this, important things have space to grow - friendships, confidence, expertise and, from a funding perspective, grant-making outputs that have a transformational impact on people's lives.

Flexibility, honesty, dignity, diversity and respect are just some of the shared values that have helped steer our work alongside beneficiaries.

3. Be comfortable with uncertainty

If funders genuinely want to put beneficiaries first, it is important to be able to 'get comfortable' with uncertainty. For some funders, letting go of specific frameworks, deadlines and processes can feel like a huge challenge. And it can be. But it does not have to be about throwing them away completely. It can simply be trying something different. When working alongside people, a funder does not have to have everything figured out at the start. Letting things emerge organically, and with input and guidance from beneficiaries, creates something far more meaningful and, in our experience, effective.

Example: Life Changes Trust events often embrace the tricky balance between planning and uncertainty, providing a structure that also enables people to shape and influence events as they happen. This could be a ‘storytelling’ session with people living with dementia or unpaid carers, where stories emerge in real time. Participants together create the life of a fictitious character which experiences the issues they face in their own lives, and the identification of these issues can then go on to influence policy and practice. Or it could be a participatory grant-making event, where ideas are created and refined and young people are given the power to make funding decisions there and then.

4. Transfer real power to people

This way of working is about recognising power dynamics and attempting to create a better balance. Putting beneficiaries first and taking a rights-based approach are non-negotiables for the Trust. Sharing power and supporting people to understand and exercise their rights improves everything that we do and takes us closer to our mission. Staff at the Trust bring lots of ideas, expertise and resources to the table too. Co-production is the magical thing that happens when we sit in the same space as equals. The ideas and solutions that we generate are better, the assumptions that are challenged improve us as people and practitioners, and the wider change that happens is transformational.

Example: In November 2020, the Dementia Programme launched a funding opportunity in response to the Covid-19 pandemic called ‘Caring for The Carer’, which provided grants of up to £1,000 to unpaid carers of people living with dementia. Inspired by the ‘Keep Well Fund’ delivered by the Young People with Care Experience Programme earlier in 2020, the aim of ‘Caring for The Carer’ was to focus on improving the physical and mental health and wellbeing of unpaid carers, and support them to cope with social distancing and isolation. By allowing them to decide for themselves how they wanted to spend their grant, we wanted them to know that they had trust, respect and autonomy. The decision panel for applications consisted of six people who were, or had previously been, an unpaid carer of someone living with dementia, so while the Trust offered administrative support, advice and guidance, the panel – those with lived experience - had the final say on which applications were successful or not.

5. Be ambitious for and with people

The Trust was established to be pioneering and deliver transformational outcomes for people, and these foundations underpin our work alongside people living with dementia, unpaid carers and young people with care experience. Of course, we maintain a commitment to safe, genuine and creative participation and engagement, but we also take risks together.

The adherence to doing something just because it’s the way it has always been done in funding practice stifles creativity, quietens voices and places limits on what feels possible. Being ambitious for and with beneficiaries means accepting that there will be some bumps in the road, and funders may even do some things that they’ll never do again. However, from our experience, those moments will be far outweighed by outcomes that will be impactful, and change how funding practices can be approached in a collaborative way.

The who, what, where, when, and how of putting beneficiaries first

From the outset, beneficiaries have been integral to what the Trust has set out to do and how we have worked across all stages of our funding management processes. The Trust believes that, unless it sets a standard for meaningful involvement and partnership with the people we're here for, it cannot reasonably ask other funders to do the same.

1. Setting and refreshing our funding strategy

Since the beginning, beneficiaries have informed what the Trust has decided to fund. Before producing our first strategy in 2015, we asked beneficiaries what mattered to them, providing a range of accessible opportunities for them to share their thoughts, opinions and experiences.

Both Programmes developed relationships with individuals who went on to take up the role of Advisors, and who became integrated into the Trust's work. Their ongoing role has been to provide expert opinion, guidance and decision-making on a regular basis to the Trust. They have also inspired us and generated ideas and innovation.

Beneficiaries also informed the Trust's refreshed strategy in 2019, not least by changing how we described people. Instead of 'care experienced young people', young people themselves told us they preferred to be called 'young people with care experience'. Their care experience, while a significant part of their identity, was not their whole identity and they did not want to be defined by it.

Likewise, our language changed in relation to ‘people affected by dementia’. Unpaid carers were clear they wanted to be recognised in their own right, not as an extension of the person with dementia they cared for. So, our language changed to ‘people with dementia and unpaid carers of people with dementia’.

Young people from the Advisory Group also attended Programme Committee meetings and continue to share insights and expertise to help inform Trustees decisions around the strategic direction of the Young People with Care Experience Programme (including decisions around new programme and funding initiative development).

2. Designing, developing and delivering funding initiatives - what we do as a funder, and what we encourage others to do

The Trust has always involved young people with care experience, people living with dementia, and unpaid carers of people with dementia in the development and delivery of funding initiatives, as well as evaluation and learning and influencing activities.

As a matter of routine, beneficiaries shape or comment on draft content such as applicant forms and guidance documents. For example, the funding criteria for the application materials for the Dementia Programme’s Befriending and Peer Support programmes were reviewed by people living with dementia and unpaid carers.

The Trust has supported beneficiaries to contribute to the development of funding proposals. For example, people living with dementia and unpaid carers of people with dementia helped to develop the concept of the Dementia Inclusive Singing Network¹ before it opened to competitive tender.

¹ Dementia Inclusive Singing Network - <https://www.lifechangestrust.org.uk/project/dementia-inclusive-singing-network>

Likewise, the Trust's Home and Belonging initiative² has involved young people with care experience in every aspect of development, design and delivery. A small team of Advisors with care experience worked alongside the Trust to develop and launch the initiative. They also provided consultancy support to potential applicants to share their skills and ensure that all projects embraced the principles of co-design and fully engaged with young people. As a result, young people are now involved in multiple roles in relation to the delivery, oversight and evaluation of these funded projects.

Applicants for Life Changes Trust funding are required to explain how beneficiaries have been involved in planning their proposed project e.g. what it will provide and its anticipated benefits for people. If the application is successful, they need to explain how beneficiaries will be involved in shaping how the project will be delivered, and how they can take part in project evaluation, giving their views about its impact and related learning. In the same vein, awardee monitoring forms ask for evidence of the above, quantitative and qualitative.

Following the publication of two key resources³ written by people living with dementia, the Trust launched a funding programme offering grants to both people living with dementia and unpaid carers to create their own Peer-to-Peer Resources. Application and guidance materials were reviewed by people with dementia and unpaid carers to ensure the language, style and design were appropriate.



2 Go to Home and Belonging and click on the arrows to scroll through projects:

<https://www.lifechangestrust.org.uk/young-people-care-experience>

3 'Dementia and Sensory Challenges – Dementia Can Be More Than Memory' by Agnes Houston - <https://www.lifechangestrust.org.uk/project/dementia-and-sensory-challenges> and 'Driving and Dementia – My Experiences' by James McKillop -

<https://www.lifechangestrust.org.uk/project/driving-and-dementia>

Importantly, the grants gave beneficiaries the opportunity to develop their own resources to then be shared for the benefit of other people with dementia and unpaid carers.

Supporting beneficiaries to take the lead role in developing and delivering projects is an important way of sharing trust, so we have provided a variety of funding to beneficiary-led groups to enable them to deliver projects. On a national level, this includes significant investment in the DEEP network (Dementia Engagement and Empowerment Project), and in tide's

(Together in Dementia Everyday) work in Scotland with unpaid carers of people living with dementia. In addition, the Trust's 'By Carers for Carers' initiative provided funding and direct facilitation to enable unpaid carers to plan, organise and deliver their own event – 'Dementia: the Carer's Experience (Better Enabled, Better Equipped)'⁴. This resulted in a number of local and national resources, and an external evaluation report⁵

On a local level, we provided funding for administrative support to the Fife-based group, STAND (Striving Towards A New Day), in their role as Learning Network Co-ordinator for Creating Better Lives Small Grants recipients in Fife. People living with dementia take the lead in providing advice and support to local groups as they deliver their projects.



4 <https://www.lifechangestrust.org.uk/project/conferences-and-carers>

5 <https://www.lifechangestrust.org.uk/sites/default/files/publication/files/CARERS%20EAST%20LOTHIAN%20REPORT%20WEB%20VERSION.pdf>

At the same time, an obvious approach to putting beneficiaries first is to fund them directly as individuals.⁶ Please also read the Strategic Funding booklet for more on this approach.

As a funder that wants to ensure beneficiaries are genuinely the priority when designing, developing and delivering funding initiatives, we require the projects which we fund to embed these principles when they in turn are distributing grants.

This is also the case for all of the Trust's legacy investments which are funded to continue to operate after the Trust has closed.

3. Assessment of funding applications and funding decisions

Beneficiaries are consistently involved in the next stage of funding initiatives - assessing and scoring individual applications, shortlisting, and taking part in decisions to fund an application and agreeing feedback as to the reasons if not. Over time, the Trust's approach has developed further, with more decision-making power resting with young people, people living with dementia and unpaid carers.

Assessment

The Trust's preferred way of working is for young people, people living with dementia and unpaid carers to be involved in the complete funding cycle i.e. from development and design right through to assessing ideas, making decisions and reviewing impact. However, we recognise that this level of involvement is not always necessary or possible, but it is worthwhile to involve people in any part of the process.

The Trust has valued the insight and opinion on funding proposals which beneficiaries have offered. Their influence has been significant and meaningful even if they have not been involved in the final decision-making e.g. by highlighting areas of a proposal that need further thought.

⁶ <https://www.lifechangestrust.org.uk/individual-awards-scheme-evidence-and-learning>

Decision-making

Offering genuine decision-making power to people living with dementia, unpaid carers and young people has been key to the Trust's approach to putting beneficiaries first. Trust staff may of course provide background information and guidance, and occasionally support to ensure fairness and consistency.

Example: The Dementia Programme's Creating Better Lives Small Grants Programme offered grants to local, grassroots organisations in all 14 health board areas. The decision-making panels were all a small group of local people, which included, where possible, people with dementia, unpaid carers of people with dementia, and locally-based professionals and stakeholders with knowledge of dementia issues in their communities. Each local panel was responsible for awarding funding in its region.

Example: An early initiative to involve young people with care experience in a decision-making role was Aspirational Awards.⁷ Aspirational Awards were co-produced with the Programme's Advisory Group from start to finish. While most of the work was undertaken by the Advisory Group in a voluntary capacity, Advisors were also paid as Grant Assessors to make decisions on who would receive an individual grant. The Trust worked with Advisors to develop a process that made best use of their time and expertise. Assessment training was provided, clear roles and responsibilities were developed and we had honest conversations about remuneration. Learning from each round of Aspirational Awards has enabled the Trust and Advisors to refine processes and deepen expertise and relationships.

⁷ Aspirational Awards: <https://www.lifechangestrust.org.uk/project/aspirational-awards>

This learning has influenced decision-making practice in other Trust initiatives and is now being shared with organisations funded by the Trust to deliver their own participatory grant-making projects through the Young Funders initiative.

Example: The National Leadership Network (NLN) for Young People with Care Experience (a Trust Legacy initiative) also involves a panel of 12 young people who independently assessed Expressions of Interest from those wishing to host the NLN, before convening as a panel to agree collective scores and create a shortlist. The panel then nominated two of their members to conduct interviews and met again to decide the final configuration of the collaboration which will host and deliver the Network. Trust staff supported the process but the young people led the decision-making.



Responsibility and empowerment

When putting beneficiaries first during the decision-making process, it is important to the Trust that we retain ultimate responsibility. Asking beneficiaries to offer advice or make the final decision on funding applications does not weaken the Trust's ownership or management of the decision-making process. Beneficiaries' participation strengthens the decision-making process as it brings validity and partnership to a process which ultimately is co-production.

Involving beneficiaries in the assessment process takes a lot of time, and the investment is significant: it's an emotional, personal and professional investment for everybody. It's very important for funders to think about how they might involve beneficiaries in decision-making if they have not been involved in their work at an earlier stage.

Meaningful involvement avoids tokenism, and it promotes people as individuals rather than representatives of an experience or a condition. Ideally therefore, funders should involve people from the start and throughout as many stages as possible.

Inclusion – known expertise and new perspectives

Funders need to decide when to call upon beneficiaries with whom they have existing relationships or when they need to involve new people.

Example: For our ‘Caring for The Carer’ fund, when we wanted unpaid carers to take the lead in making the awards, we were able to call on people we had worked with regularly in the past. Working in pairs, the six current or former carers reviewed their allocated applications, bringing preliminary decisions to a meeting with Trust staff. With guidance from staff, if needed, the panel then decided which applications were successful. Developing relationships with beneficiaries over a long period of time is a valuable investment. It also means a funder may also be able to call on people at short notice for smaller tasks that require their insight and experience but also a quick turnaround.

Funders might want to consider the need for decision-makers to understand and ‘buy into’ their funding approach. This will strengthen the decision-making team and reduce the risk of disagreement or confusion. Other key issues to consider include the value of beneficiaries’ expertise by virtue of their lived experience, the particular experience of the individuals involved, the importance of fairness, the need for diversity, and the working relationship between different beneficiaries.

When funders have made the decision to involve beneficiaries in the assessment process, our experience is to always remember to be flexible and support people to step out and step back in, as *they* prefer or need. Funders should discuss and agree beforehand which roles are voluntary and which should be paid (including expenses).

And finally, don’t forget to recognise what the funder brings to the table – co-production is about everyone bringing something important and funders need to be clear about their responsibilities too.

4. Taking part in evaluation, identifying learning, defining impact

All successful funding applications and proposals detail how beneficiaries are to be involved in project evaluation and how they will participate in a range of ways, including giving feedback on the impact of the project, reviewing evaluation findings and conclusions, and being recruited as volunteer evaluators themselves with support, training and expenses provided.

Funded organisations are expected to evidence beneficiaries' involvement in their self-evaluation, and beneficiaries have contributed to project evaluation through feedback, interviews and case studies.

Taking an extra step and engaging beneficiaries as co-researchers is also empowering and effective. It brings valuable knowledge and lived experience to the investigative process.

Examples: When the Trust commissioned HammondCare to undertake an evaluation of the Dementia Programme's largest investment - over £8m invested in Dementia Friendly Communities⁸ - people with dementia and unpaid carers were recruited as peer researchers, focus group participants, and programme advisory group members.

8 Dementia Friendly Communities - Evidence and Learning
<https://www.lifechangestrust.org.uk/dementia-friendly-communities-evidence-and-learning>
Dementia Friendly Communities – individual projects
<https://www.lifechangestrust.org.uk/our-dementia-programme>

When the Trust commissions independent evaluators, beneficiaries also play a key part - shaping the commissioning brief, assessing and scoring proposals, interviewing shortlisted candidates, participating in the decision about who will be awarded the contact, and in agreeing feedback to unsuccessful bidders.

Having commissioned external evaluations of all major funding initiatives, the Trust engaged the University of Stirling and Ipsos MORI to undertake an overall evaluation of the Trust's work. People living with dementia, unpaid carers, and young people with care experience were recruited as co-researchers, and played key roles in the gathering and sharing of learning from the evaluation.

Beneficiaries have also contributed to other discussions and consultations including Trust-funded initiatives such as the Technology and Dementia report⁹ which incorporated workshops and discussions, and Studio LR's project to design accessible symbols and signs. Along with the several projects in our Transport and Dementia strand, these projects relied on the ongoing participation of beneficiaries.



9 Dementia and Technology – Evidence and Learning <https://www.lifechangestrust.org.uk/technology-and-dementia-evidence-and-learning>

5. Communicating learning and impact

The Trust believes that there are many different ways to involve people in communicating learning and impact. The first-hand testimony of beneficiaries is undeniably powerful as only they can describe what it means for them to live with dementia, or to care for someone with dementia, or to have experience of the care system. However, we also know that putting beneficiaries first should never come with an expectation for people to share their own story or ‘sell their soul’. People should always feel in control of their story and be supported to make decisions about what and how they want to share personal information (if at all).

This has been particularly important for young people with care experience. The Trust nurtures and values the ideas, skills and commitment that young people bring to our work, and does not focus on their story. We build on what people are good at and we remain focused on a future-oriented agenda. In return, learning and impact is focused on amplifying what works in achieving transformational change.

Our ‘knowledge into action’ approach means we share learning as it becomes available, and take stock of learning to date when deciding what to fund next. For example, in 2015 we invested £3.4m in 14 Dementia Friendly Communities. We then gathered learning from the projects, met with them regularly, assessed their impact, and undertook an evaluation of the funding programme. With that learning, we then developed a different approach to Phase 2. We invested more than £5m of additional funding with the aim of *building on* what the Phase 1 projects had achieved, asking projects to *explore further* what dementia friendly communities are, and *how* they might deliver positive outcomes for people living with dementia and unpaid carers.

Part of the new approach in Phase 2 was to offer more development grants, as well as continuation funding for successful Phase 1 projects, all of which resulted in a total investment of £8.6m in 40 projects over six years. Nine key principles were established as part of a toolkit¹⁰ for organisations wishing to establish or develop their own dementia friendly community.

Roles in communicating learning and impact

When running events to share evidence, learning and impact, beneficiaries can have a key role in communicating the learning, given their perspectives on the benefits and impact of a project the Trust has funded. Supporting beneficiaries to present and promote their project work can be rewarding and powerful, but it can also be emotional and demanding.

Throughout the existence of the Trust, we have been able to welcome our beneficiaries to express themselves at a wide range of events and activities – physical events, online events, resources, attending panels, giving presentations, creative media including film, song and visual art, and many more. Putting beneficiaries first involves looking at everything a funder does and exploring ways in which beneficiaries can be involved. If beneficiaries are not involved, ask why not, and can something be done to enable it?

‘Loud & Clear’¹¹ is a report commissioned by the Trust which explores two decades of rights-based activism by people living with dementia in Scotland. The report has a twin booklet offering practical advice and tips to other dementia activists and supporters.

¹⁰Dementia Friendly Communities - Toolkit: https://www.lifechangestrust.org.uk/sites/default/files/publication/files/DFCs%20Toolkit%20WEB_0.pdf

¹¹Loud & Clear: Exploring two decades of involvement, voice and activism by people with dementia in Scotland - <https://www.lifechangestrust.org.uk/project/loud-clear-exploring-two-decades-involvement-voice-and-activism-people-dementia-scotland>

Our Voice & Vision¹² event focused on the power of creativity for young people with care experience. Young people were central, from planning and delivering sessions to curating and showcasing creative outputs. The Voice & Vision Gallery, an online space built by the Trust with the support of talented young Gallery Curators, represents what is possible when you put beneficiaries first; it is full of energy, pride, opportunity and inspiration.

Community events - physical and online - have always been an extremely important part of the Trust's approach to learning and influencing. They have taken place in concert halls, hotels and various community venues, as well as online, with beneficiaries integral to their organisation and delivery.

Example: the Dementia Programme's 14 'Community & Dementia'¹³ regional events ran from 2018 to 2021, moving online during the pandemic. At each event, people living with dementia and unpaid carers could be Co-Chairs, members of discussion panels, speakers and guests, with different approaches being adopted to support their active involvement.



12 Voice and Vision – Creativity and Care Experience - <https://www.lifechangestrust.org.uk/project/voice-and-vision-creativity-and-care-experience>

13 Community & Dementia: Creating Better Lives – Regional Events - <https://www.lifechangestrust.org.uk/project/community-and-dementia-creating-better-lives-regional-events-and-grants>

Conclusions

We recognise there are characteristics of the Trust that have enabled us to pursue participatory approaches – our strategic focus, our independence, a guaranteed budget and an agreed timeframe for spending that budget. We also know that working closely with beneficiaries is emotional and personal, and it takes significant investment in and from people to do it properly. So, why bother?

Working in this way has had a profound impact on everyone involved, from staff to volunteers, advisers, awardees and others. It has enabled the Trust to connect with people living with dementia, unpaid carers of people with dementia and young people with care experience in ways that staff alone would never have been able to do. Assumptions have been questioned, processes have been tailored, words have been thoughtfully chosen and risks have been carefully considered.

People with lived experience have been involved in wide-ranging activities alongside the Trust. For some funders, it may feel too difficult to find the resource required to work in this way. In response, we would always say this is not about additional time or money.

It's about changing *how* you spend your time and money *right now*. Putting beneficiaries first transforms lives and redefines grant-making.

Here again are our top tips:

- ▶ Invest in positive relationships
- ▶ Stay focused on shared values
- ▶ Be comfortable with uncertainty
- ▶ Transfer real power to people
- ▶ Be ambitious for and with people.

