

# An impact briefing for the About Dementia programme 2019-23

**How About Dementia has supported people living with dementia and unpaid carers to shape the policy and practice affecting their everyday lives**

Produced by Matter of Focus in collaboration with the About Dementia team, March 2023



## At a glance

**Age Scotland** is the national charity for older people.

**About Dementia** is Age Scotland's Forum for improving the lives of people living with dementia and the unpaid carers of people living with dementia.

The programme aims to contribute to making Scotland a place where people living with dementia and unpaid carers can live with dignity and in full enjoyment of their Human Rights. It has covered many areas of life, including transport, housing, technology and care. The programme uses **Human Rights** as a framework to help people understand all the different rights, in different areas of life, that people living with dementia need to realise to experience dignity and inclusion.

**Matter of Focus** has been the learning partner for About Dementia from 2019 to 2023. Matter of Focus is a mission led company that supports organisations to understand if and how their actions really do make a difference for the people and communities they care about.

**This impact briefing** is produced by Matter of Focus, based on four years' work supporting About Dementia. It is intended to relay the learning from this programme to decision-makers and practitioners supporting people living with dementia in their communities.

**About Dementia has an important story to share**, on bridging the very different worlds of people's day-to-day experiences of dementia

and policy-making. The story of the programme is also the story of the growth of a strong, vibrant and diverse community of people living with dementia/providing unpaid care, bringing their knowledge by experience, talents and skills to the task of making things better for themselves and others.

*Members of the About Dementia community meeting*



## The changes About Dementia wants to see are rooted in evidence

- About Dementia takes a community-led and human rights-based approach. A human rights-based approach leads us to look at all the issues that may be important to people living with dementia/unpaid carers.
- People consistently tell About Dementia that they want continuity of care and choice in support.
- More community-based and person-centred support is important so people can live well after diagnosis.
- These are clear messages which are confirmed in the learning drawn together by the Life Changes Trust.



*Poster by stakeholders showing their hopes for the new National Dementia Strategy. The poster shows a person with dementia living in their own home and surrounded by those they love. The person was able to access local supports including a Meeting Centre and Self-Directed Support to make the connections possible. Note the safety net which prevents anyone from slipping through the gaps in support in the community.*

## Together with people living with dementia/unpaid carers, About Dementia has built a community

- Community members come into a safe space, share experiences of dementia and have opportunities for wider influence.
- About Dementia works with people in different ways to suit the needs of individuals.
- With expert facilitation, the community is wide enough to hold lots of different views and experiences.
- The connection with lived experience, foundational to the programme's work, relies on inspiring positive feelings about the programme and sustaining people's involvement.

### Timeline of key points of engagement

**2019**

About Dementia reached out to and built networks of people with lived experience

**2020**

About Dementia focused on quality of engagement and building the community

Produced a Manifesto for Human Rights for people living with dementia and unpaid carers, communicating members' concerns in preparation for the Scottish Parliament elections

**2021**

Brought together people living with dementia / unpaid carers and decision-makers, e.g. Meet the Minister and Carers Question Time with MSPs

Supported people's engagement in the National Care Service consultation through engagement sessions and accessible information

**2022**

Regular groups for unpaid carers and people living with dementia have continued to be supported

267 people took part in About Dementia's consultation around the National Dementia Strategy

160 engagement packs distributed, so people could replicate this inclusive engagement in their own settings

People living with dementia and unpaid carers were involved in co-creating grants programmes managed by About Dementia

## By developing thoughtful and creative ways of working, About Dementia has been able to include more people living with dementia and their unpaid carers in the conversation

- In the support offered by the programme, community members highlight, 'being supported', 'valued', 'made welcome' and the flexibility and generosity they have experienced.
- Members value warmth, laughter, friendship and peer support.
- About Dementia has developed and shared an innovative story-telling approach to widen the conversation into different geographic communities and include people living at various stages of dementia.



*About Dementia helped people who may not otherwise have been able to, to engage in conversations about the new National Dementia Strategy*

## Being involved makes a direct difference to community members

- Through the lifetime of the programme, the team has been inspired by watching activists grow in confidence and find their voice in policy and practice discussions.
- Involvement can lead to increased self-worth and a sense of purpose.
- While lighter touch ways of being involved can include more people in the conversation, members who have invested deeply in this work over time have been on a significant personal journey.

“Being asked to be included in these sort of things gives me a feeling of self-worth, a purpose in life. It's highly important because these things are stripped away from you when you're diagnosed with dementia and to be involved in this kind of thing is second to none.”

“ — Activist living with dementia

“The role is a rewarding one and that of being a much valued and completely supported community member amongst equals, together with the ability to say exactly what you feel and how you are feeling in a safe space at our meetings, amongst those who are perhaps in similar circumstances or experiences as yourself.”

— Member of the About Dementia community

## Valuing the contributions of people living with dementia/unpaid carers leads to wider conversations and wider knowledge about what will make difference

- A core belief of the About Dementia programme is that it is important to value different forms of knowledge including knowledge by experience.
- About Dementia provides safe and supportive spaces for conversations to happen, linking the worlds of policy-making and everyday experience both directly and indirectly.
- At times, this work has challenged expectations of what people living with dementia can accomplish.

“We have been very encouraged by the approach of your team - despite the seriousness of dementia and its effects on people, you are demonstrating that it is possible to have positive

and optimistic conversations on the subject and this is proving to be infectious!”

— Cowal Elderly Befrienders, Dunoon, who hosted an engagement session with the About Dementia team on the National Dementia Strategy

“So [working with About Dementia including learning from their storytelling approach] has been a really positive part of the process, which has kind of underpinned the work to develop a new [Dementia] Strategy that is reflective of a wider range of voices and experiences from previous ones.”

— Policy-maker

## Listening and responding to the views of people living with dementia and unpaid carers is key to making transformational change

- About Dementia has celebrated good practice from around Scotland and worked in broad partnerships to showcase this.
- The programme builds alliances and makes connections to strengthen the collective influence of those advocating for community-based support.
- Some progress has been made in making the case for community-based supports such as Dementia Friendly Communities and Meeting Centres.



### Investment in community-based supports

Members have consistently highlighted the importance of living well post-diagnosis and the losses of different kinds that people experience at this time. About Dementia has contributed to the collective influence of the sector in calling for better recognition of grassroots approaches to post-diagnostic support such as the work of Dementia Friendly Communities. Social contact, connections and stimulation are integral to living well with dementia.



“Being diagnosed with dementia is so often about loss; driving licence, friends. You want to maintain a lifestyle that’s as normal as possible and keep in touch with people ... keep active as much as possible to keep the brain going.” — Person living with dementia

In 2021, the Minister for Mental Wellbeing and Social Care announced £1m funding to support Dementia Friendly Communities. About Dementia was invited to work in partnership with The Scottish Government to distribute this funding. Scottish Government has specifically cited this fund as a form of recognition of the importance of community-led support to people living with dementia and unpaid carers, in this period of Covid recovery.

## Becoming a legacy partner of the Life Changes Trust and a grant-



## maker gives About Dementia new ways of making a difference

- As a legacy partner of the Life Changes Trust, About Dementia will support a community of learning and practice around Dementia Friendly Communities. It holds the bank of learning and evidence gathered by the Trust.
- About Dementia is developing novel practices in co-producing grants programmes with people with lived experience of dementia, including paying people for their time and expertise.



### Involving people with lived experience in co-producing grants programmes has brought a range of benefits

In 2022, About Dementia began working alongside people living with dementia/unpaid carers to design and distribute grants for community-based support (funded by Scottish Government, see above). Through this experience, they have built a strong group of

community members to support this work and flexible and accessible processes that enable their involvement. Involving people in this way helps keep the focus on funding activities that will really make a difference to people on the ground.

In 2023, About Dementia began work on Life Changes Trust Legacy programmes including peer-to-peer grants. These offer funding to individuals/groups with lived experience of dementia who want to take forward a project to benefit their peers. Designing the programme alongside community members has kept focus on making the application process as simple and accessible as possible, to attract and bring on a new group of dementia activists. Those designing the programme hope to reach out and provide direct support to applicants and beneficiaries again keeping peer-to-peer support in mind.

## More information

For more information about About Dementia and to access the Life Changes Trust Resource Collection:

<https://www.ageuk.org.uk/scotland/what-we-do/dementia/about-dementia/>

 [@AboutDementiaSc](https://twitter.com/AboutDementiaSc)

For more information about what Meeting Centres are:

<https://www.ageuk.org.uk/scotland/what-we-do/dementia/about-dementia/meeting-centres/>

For more information about Matter of Focus and how we support organisations to tell their story of the difference they make:

<https://www.matter-of-focus.com/>

 [@Matter\\_of\\_Focus](https://twitter.com/Matter_of_Focus)

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*Members of the About Dementia community*

“When people see the word ‘dementia’, they make a variety of assumptions that are not accurate – people assume that if you have dementia you can’t think. And that’s rubbish.”

— Person Living with Dementia