



Annual report
2021 - 2022

**People with
dementia driving
positive change**

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Welcome from the co-chairs of Dementia NI

John McErlane and Adele Faulkner

Welcome to the Dementia NI annual report for 2021 - 2022.

We hope you enjoy reading about the achievements that have been made during this time. It has been an eventful year, and we have seen great change and growth in Dementia NI.

As co-chairs of the board of Dementia NI, we are delighted to see the progress that has been made in delivering our strategy. There is a particular focus on Campaigning, Membership and Sustainability, and these will continue to be priority areas for us going forward.

We are proud to lead such a dynamic and unique organisation, and we want to thank all board members, staff, members and volunteers for their vital contribution to our continued success.

Our Vision

Everyone living well with dementia

Our Mission

People with dementia driving positive change

Our Values

- Led by people with dementia
- Inclusive and accessible
- Striving for meaningful change
- Being heard and understood

Member Led

We are an organisation set up by people with dementia, for people with dementia. All our members have a diagnosis of dementia and are at the heart of everything we do.

Partnership Working

We work with a wide range of groups to raise awareness and improve services for people with dementia. These include the Department for Health, PSNI, Alzheimer's Society, Make the Call and DEEP, the UK network of Dementia voices.



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Volunteering

We have a fantastic team of volunteers, and they are highly valued contributors to the success of Dementia NI. Our roles range from helping at our empowerment groups, volunteer drivers, to our fundraising volunteers. We could not achieve what we do without their support.



Our Strategy and Goals

The strategic plan was launched in March 2020 and was due to run from 2020 – 2023. The COVID-19 pandemic impacted our ability to deliver on the strategy.

The Board has subsequently agreed that the strategy will now cover the period 2020 – 2024. The Board has also identified three priority areas within the strategy; Campaigning, Membership and Sustainability. Throughout the report we outline our achievements against our key goals.

Public Benefit

All our activities are related to one or more of the following charitable objects:

- Challenging the stigma of dementia
- Providing support to people living with dementia so that they may raise awareness in their own right
- Promoting the rights of people living with dementia to be involved in decisions that affect their lives
- Providing training, education and awareness of dementia to the public and organisations throughout the UK and Ireland

The Board has considered the Charity Commission for Northern Ireland guidance on public benefit.

Dementia Journey

Reduce the impact of a dementia diagnosis throughout the journey

When a member joins Dementia NI, staff now carry out a personal assessment which includes measurement of their confidence and wellbeing. This is reviewed every six months to monitor any changes. This will help us report on impact in future.

"I live with dementia and I am a member of Dementia NI. Living with dementia is very hard most of the time, but with the help I get from Dementia NI, my diagnosis is easier to cope with. I look forward to meeting up with everyone at the face to face and Zoom groups"

Martin, Belfast group member



Dementia NI worked with the Dementia Companion team in Craigavon Hospital on how to support people with early-onset dementia in a hospital environment. This led to changes in practice within the ward and collaboration on the re-design of the ward.

Dementia NI are working with the Southern Health and Social Care Trust on an online training programme for dementia. This will be for all healthcare professionals across Northern Ireland. Members are contributing to the design and content, ensuring the voice of people with dementia is an integral part of the training.

We listened to our members when they told us that a Dementia NI photographic ID card would help them feel more confident when they are engaging with the public and accessing services. All members can now access an ID card and feedback has shown this has increased their confidence when accessing services and engaging with their community.

Campaigning

Campaigns led by people with dementia to influence policy and practice locally, nationally and globally

Dementia NI successfully secured the support of the PSNI to have the Herbert Protocol introduced in Northern Ireland. This is a lifesaving initiative to trace people with dementia who go missing more quickly.

Dementia NI members were involved at every step of the process and contributed to the content, design and messaging of materials.

The protocol was successfully piloted within Armagh, Banbridge and Craigavon Borough Council in 2021 and subsequently launched regionally in September 2022, with endorsement from the Health Minister, Robin Swann.

Dementia NI members responded to the Department of Health's draft Advance Care Planning Policy to ensure the views and experiences of people living with dementia were heard.

Members welcomed the policy to ensure individual choices are respected, including plans for future healthcare. Our members also identified that it requires further work and identified key changes needed for successful implementation of the policy.

- Support to complete the Advance Care Plan early in the dementia journey
- Support from a healthcare professional to complete and Advance Care Plan
- Inclusion of timings for the Advance Care Plan conversations and reviews

Dementia NI members also actively participated in the Marie Curie End of Life Election Hustings Event, highlighting the issues above.



Membership

Developing the membership of Dementia NI

We grew our membership from 44 to 72, and our network of empowerment groups from 7 pre-pandemic in 2020 to 12 in 2022.

A challenge during this period was facilitating the return to face to face activity safely. Our empowerment team carried out in person home visits with each member across Northern Ireland before face to face activity resumed. This was to ensure the groups would still provide a safe and empowering place for each member.

We listened to our members when they told us they wanted to keep some virtual activity and we now have a blend of face to face and virtual activity.

We continue to offer members opportunities for personal development. Members interested in supporting others are trained to develop peer support skills. Our more established members have been providing 'In the Same Boat' peer support to newly diagnosed members.



**Driving
positive
change.**



Education and Awareness

Improve education and awareness about dementia to make communities more inclusive and welcoming for people with dementia.

Dementia NI worked with the BBC on a campaign to raise awareness about dementia. Members presented the broadcast appeal which was aired on BBC Radio Ulster and the BBC NI appeals website.

Our members worked with the Shared History Interpretive Project (SHIP) to co-produce a book, 'Recalling past memories'. Members helped design the book content to make the book more accessible for people living with dementia.

Dementia NI delivered training sessions to over 60 students from Ulster University's Speech and Language Therapy department and students on the MSC in Dementia Studies programme at Stirling University on living with dementia.

Sustainability

Review and develop organisational structures to ensure the sustainability of the organisation.

Dementia NI made important changes to the staffing structure and resources to ensure effective delivery of our strategy.

We reviewed our empowerment team, amended existing roles and introduced new roles to allow us to deliver work and engage with members more effectively.

We introduced new roles to the organisation, welcomed a Communications Officer post and expanded our fundraising team.

As a result of these changes we have been able to support a growth in our membership, income generations and communications activity.



We carried out a review of all our financial and human resources policies and processes to ensure best practice.

We invested in and launched a new customer relationship management system (CRM), Salesforce. This allows us to work much more effectively.

These developments have ensured we can support our growth in a sustainable way.

We invested in communications, launching a new website and growing our social media presence.



Facebook
followers

6,845

An increase of

38%



Twitter
followers

3,680

An increase of

3,267%



LinkedIn
followers

280

An increase of

28.7%



Instagram
followers

1,179

An increase of

450%

Financial review

Unrestricted reserves

Unrestricted reserves as of 31 March 2022 were £363,013.

The Trustees have reviewed the reserves policy and Dementia NI now operates a six month reserve policy. This covers six months of essential running costs for the charity of £228,412.

In addition to this Dementia NI holds £50,000 designated reserves to support the National Lottery funding if required.

Our remaining free reserves of £84,601 are essential to support our transition from large grant funding over the next two years.

The total income for the year was £472,739 of which £181,292 was raised from grants and £291,447 from donations and gift aid.

Income Generation

The support from the public, our corporate partners, our volunteers and all our supporters during this period has been immense, enabling the fundraising team to raise an incredible £291,447.

Our fundraising continues to develop and diversify. We have invested in building a strong fundraising team who work closely with our members and volunteers.

Our fundraising is also supported by our ever growing profile. This is closely linked to the investment in our Communications role. It also reflects the strength and commitment of our members who share their stories and experience with the wider public and regularly participate in media opportunities.

We continued to secure successful charity partnerships. Two are highlighted below:

- Price Waterhouse Coopers opened their doors to our Belfast Empowerment Groups, providing a welcoming and uplifting environment for members to meet
- Calvert joined us for a two year partnership which launched with a gift in kind of a new £2500 photocopier machine. As well as raising vital funds, Calvert offer us use of office space and regularly volunteer with Dementia NI activities

We would like to recognise every amazing supporter who chooses to support our work and believes in who we are and what we do.

Grant Funding

The National Lottery Fund - Empower and Support Programme

In 2019 Dementia NI secured £458,000 from the National Lottery Fund over four years, to develop and deliver a Northern Ireland wide Empower and Support Programme. This programme started in October 2019 and will run until October 2023.

COVID-19 and the associated restrictions had a significant impact on delivery and resulted in an underspend in the first two years of the programme.

We agreed a proposal to reinvest this underspend and this meant that in 2021 we were able to invest in the staff team delivering the programme. We welcomed two new empowerment facilitator posts, as well as an empowerment administrator post.

Department of Health - Mental Health Fund

We were successful in our application to the Mental Health Fund and have been awarded £99,540 over two years. This will support the delivery of the the programme 'Dementia Diagnosis - a tailored approach to promoting positive mental health and living well with dementia. This award will fund three additional part time empowerment facilitator posts.

Department of Health - Short Breaks Fund

Dementia NI continued to successfully deliver the contract for the Short Breaks initiative on behalf of the Department of Health. This initiative provides a tailored hotel break package to people living with dementia and their family / informal carers.

Small grants from the John Moore Foundation and Arts Council NI have also supported our work with volunteers and arts based activities with our empowerment groups.

Plans for the future

We will continue to deliver our 2020 - 2024 strategic plan.

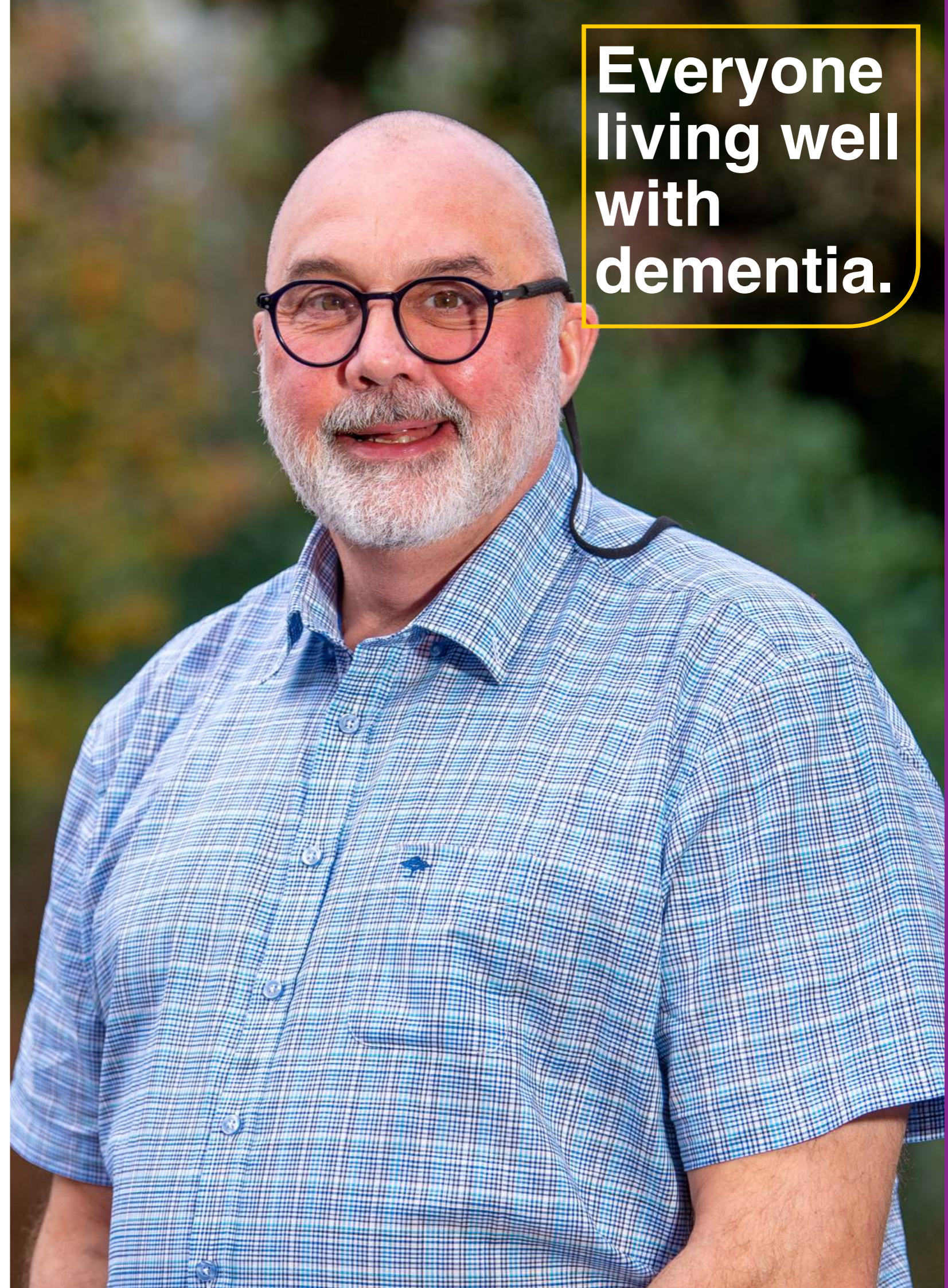
We will develop the Mental Health Fund Dementia Diagnosis programme and have recently welcomed the three new empowerment facilitator posts to our team.

We have secured funding from LFT Charitable Trust to deliver a communications project in 2023 'Dementia shouldn't stop a conversation; it should start one'. This will allow us to develop a range of resources to engage with the public and increase our reach.

We will continue to grow and develop our membership and network of empowerment groups.

We will develop campaigning in 2023, increasing our understanding of a rights based approach to campaigning and involving our members in development of this for Dementia NI.

We recognise the value of our team members; board members, staff, members and volunteers in achieving our goals. We will continue to invest in our infrastructure to support our growing team.



**Everyone
living well
with
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Structure, Governance and Management

Dementia NI is a registered charity with the Charity Commission for Northern Ireland. Our charity registration number is NIC106148. We are also a company limited by guarantee. Our company registration number is NI628713.

The company was incorporated on 15 January 2015. The company was established under a Memorandum of Association which established the objects and powers of the company and is governed by its Articles of Association.

The liability of members is limited in that every member of the company undertakes to contribute an amount not exceeding £1 in the event of the company being wound up.

The trustees, who are also directors for the purpose of company law, and who served during the year and up to the date of the signature of the financial statements were;

- Adele Faulkner (co-chair)
- John McErlane (co-chair)
- Leanne Baker (treasurer)
- Davie McElhinney
- Siobhan Donaghy
- Denise Falls
- Naomi Mainwaring (co-opted)
- Nicola Browne (co-opted)

Recruitment and appointment of Trustees

The charity Trustees are also Directors of the company. A Trustee is initially elected for a term of three years in accordance with the Articles of Association. Trustees may be re-elected for a second term, serving up to a maximum of six years.

Induction and training are provided to all new Trustees to ensure they are informed and effective in their role.

Governance

The Board of Trustees is responsible for the overall governance and strategic direction of the organisation. The chief executive has been delegated responsibility for the overall implementation and day to day management of the organisation.

The board held eight meetings during the year 2021 - 2022. In addition to the board meetings, the Finance and Risk subcommittee and the HR subcommittee meet as required. The chief executive attends all board meetings and subcommittee meetings.

Risk Management

Dementia NI has appropriate systems in place to manage risk. The board has established HR and Finance and Risk subcommittees as a key element in risk management. The board has a risk register in place which outlines the key risks and the controls in place to mitigate risk. Board members have received training in managing risk.

Independent Examiner

Muir & Addy chartered accountants were appointed as independent examiners.

Thank - you

We want to thank all our members, staff, volunteers, fundraisers and supporters for all your support this year.

We could not achieve what we do without you. We are looking forward to achieving even more with your help in 2023!

Our Values ▶



Led by people with dementia.



Inclusive and accessible.



Striving for meaningful change.



Being heard and understood.



Driving positive change.

