

Our terms of reference



The **LGBTQ+ Dementia Advisory Group** is a group of individuals who are passionate about improving the lives of all people affected by dementia who identify as LGBTQ+. We believe that the key to successfully effecting positive change is to bring together like-minded people to share ideas, knowledge, and expertise. We want to develop a network of people who will work together to achieve this common goal. We value the combined input of people with lived experience of dementia, people with experience of caring for or supporting people with dementia, and people who identify as LGBTQ+ with an interest in dementia.

Our aims are:

1. To offer regular networking opportunities for people who want to improve the lives of people affected by dementia who identify as LGBTQ+.
2. To share ideas and disseminate knowledge and best practice on how to support people affected by dementia who identify as LGBTQ+.
3. To compile helpful resources for people affected by dementia who identify as LGBTQ+ and the people who support them.

Membership of the Advisory Group

The **LGBTQ+ Dementia Advisory Group** is managed by a group of core members. Between us, we have a wealth of lived experience of dementia and of identifying as LGBTQ+. We meet monthly to discuss our projects and enquiries we receive via email. From time to time we may invite other people to join, observe, or contribute to the group. These could be:

- People with lived experience of dementia;
- Health and care professionals;
- Academics and students researching relevant topics;
- Anyone who has something to share or wants to learn more about the lives of people living with dementia who identify as LGBTQ+ and the types of support available.

If you are interested in joining the group as a core member or guest please contact us.

Who to Contact

The **LGBTQ+ Dementia Advisory Group** is run by a group of volunteers. We welcome enquiries from LGBTQ+ people living with dementia and their carers and from professionals who want to find out more about how to support LGBTQ+ people living with dementia and their carers. If you would like to get in touch, please email our email inbox: lgbtq.dementia@gmail.com

Please note, the **LGBTQ+ Dementia Advisory Group** is **not** a support group. If you are looking for support, you can find helpful information on the following websites:

- Alzheimer's Society: www.alzheimers.org.uk
- Opening Doors London: www.openingdoorslondon.org.uk – This includes the Speak Out with Dementia peer support group. Please see more information below.
- Dementia UK: www.dementiauk.org

About us



The **LGBTQ+ Dementia Advisory Group** began as a steering group in Summer 2020 with the aim of creating an online peer-support group for people living with dementia who identify as LGBTQ+. The steering group was made up of people living with dementia and their carers, as well as professionals who work with people living with dementia. Some of the members of the steering group identified as LGBTQ+ and others did not.

A pilot version of the peer support group ran successfully from November 2020 to March 2021, facilitated by Aimee Day and Lucy Whitman, with funding from the National Lottery Community Fund. The peer support group, **Speak Out with Dementia**, is now provided by [Opening Doors London](https://openingdoorslondon.org.uk), facilitated by Lucy Whitman. For more information about the peer support group, contact: info@openingdoorslondon.org.uk

In January 2021, the steering group became the **LGBTQ+ Dementia Advisory Group**. The same individuals and several new core members continue to meet with a re-defined purpose, as set out in this document. The **LGBTQ+ Dementia Advisory Group** now exists to create a networking opportunity for people who support people affected by dementia who identify as LGBTQ+.

Our core members

Our core members are involved in this group in a personal capacity. Any affiliation noted below is provided solely as reference to their expertise in supporting LGBTQ+ people living with dementia and their carers. Our current core members are:

- ❖ **Thomas Williams** (Chair) - Doctoral researcher - *University of Bath*
- ❖ **Mike Parish** - Personal experience of dementia
- ❖ **John Hammond** - Rainbow Café Development Worker - *Switchboard*
- ❖ Lucy Whitman - Dementia Engagement Officer - *Opening Doors London*
- ❖ Christine Maddocks - Personal experience of dementia
- ❖ Heather Ritchie - Personal experience of dementia
- ❖ Dáithí Clayton - Personal experience of dementia
- ❖ Natasha Howard - Senior Innovator - *Alzheimer's Society*
- ❖ Andrew Gilliver - Pride in Practice Co-ordinator - *LGBT Foundation*
- ❖ Jane Platts - Dementia Voice Lead (Wales and West Midlands) - *Alzheimer's Society*
- ❖ Julie McCaughey - Dementia Voice Lead (Northern Ireland and the North West) - *Alzheimer's Society*
- ❖ Paulette Winchester-Joseph - Consultant Admiral Nurse (Diverse and Under-served Communities) - *Dementia UK*
- ❖ Patrick Ettenes - Personal experience of dementia

The members in **bold** jointly manage the email inbox.