



## Rare Dementia Support Group Volunteer

### Role Description

#### **Purpose of the Role:**

The Rare Dementia Support Group provides a safe, understanding, and inclusive space for people living with rarer types of dementia — such as Posterior Cortical Atrophy (PCA), Primary Progressive Aphasia (PPA), behavioural variant Frontotemporal Dementia (bvFTD), and other young or atypical dementias — along with their carers and families.

The needs of people living with rarer dementias can differ significantly from those associated with more common types of dementia. Individuals may experience changes in language, visual processing, behaviour, executive function, or personality rather than primarily memory difficulties. Many may also be younger, in employment, or supporting families at the time of diagnosis.

As a Rare Dementia Support Volunteer, you will help create a respectful, informed, and supportive environment where attendees feel understood, valued, and less isolated. You will work alongside staff to ensure the group provides meaningful peer support, practical understanding, and opportunities for shared experience.

You will be part of a team that recognises the unique challenges faced by those affected by rare dementias and champions their right to appropriate support, dignity, and community connection.

**Reporting to:** Dementia Wellbeing Manager/Group Facilitator

**Location:** Gillingham Football Club

**Hours:** 4<sup>th</sup> Tuesday of every month between 19.00 & 21.00

**Expenses:** Out of pocket expenses reimbursed in line with policy

#### **The Role Responsibilities**

You will be motivated by the opportunity to support individuals and families navigating the complex and often misunderstood journey of rare dementia.

1. Welcome attendees warmly, helping to create a safe, inclusive, and non-judgemental environment.



## Rare Dementia Support Group Volunteer

2. Support group discussions, ensuring everyone has the opportunity to contribute in ways that suit their communication style and abilities.
3. Demonstrate patience and adaptability when supporting individuals who may experience communication, language, behavioural, or visual processing challenges.
4. Offer empathetic listening and companionship, recognising the emotional impact of living with or caring for someone with a rare dementia.
5. Assist with any structured activities, information sessions, or peer support discussions facilitated by staff.
6. Be mindful that some attendees may be younger or at different life stages than typically expected within dementia services.
7. Promote dignity, independence, and respect at all times.
8. Observe and report any concerns about attendees' wellbeing to the Group Facilitator or Dementia Wellbeing Coordinator.
9. Follow Alzheimer's & Dementia Support Services policies and procedures, including safeguarding, confidentiality, and health and safety.
10. Attend relevant training and briefings to build understanding of rare and atypical dementias.

This role description is not exhaustive and may be amended to reflect the needs of the charity.

**This role is subject to an Enhanced disclosure and Barring Service (DBS) check**

### PERSON SPECIFICATION

	Essential	Desirable
Skills		
Friendly, approachable and reliable	X	
Good communication and listening skills	X	
Able to work as part of a wider team	X	
Respectful, patient and non-judgemental	X	
Enthusiastic and encouraging	X	
Commitment to equality, diversity and inclusion	X	
Willingness to attend training and supervision	X	
Experience of volunteering or supporting people in a group setting		X
Knowledge of dementia and the challenges faced by those affected		X
Experience of working with older people		X
Confidence in facilitating a small group		X