‘Maintaining occupations when living with dementia’ Guideline Development Group

Person with lived experience role description

We’re RCOT, the Royal College of Occupational Therapists. We’ve championed the profession and the people behind it for over 90 years, and today we are thriving with over 36,000 members. Then and now, we’re here to help achieve life-changing breakthroughs for our members, for the people they support and for society as a whole. We want people to be at the heart of the work we do and to help us make decisions about that work. This includes having people with lived experience on our Guideline Development Group.

# What is occupational therapy?

Occupational therapy helps you live your best life at home, at work – and everywhere else. It’s about being able to do the ‘occupations’ you need, want and have to do. That could mean overcoming challenges learning at school, going to work, playing sport or simply doing the dishes.

# What is an occupational therapist?

Occupational therapists work with you to recommend adjustments to the way you live by looking at the relationship between the activities you do every day, the challenges you’re facing, and your environment.

**What is a guideline?**

Our guidelines support occupational therapists so that they can help people based on the best and latest evidence. The guidelines include recommendations for occupational therapists to follow when working with people. Each guideline focuses on a specific area of occupational therapy practice. You can view our previously published guidelines [here](https://www.rcot.co.uk/practice-resources/rcot-practice-guidelines).

This new guideline will focus on how occupational therapists can support people with dementia to do the things they need, want and have to do.

# What does the Guideline Development Group do?

The Guideline Development Group produces a guideline following the process set out in our [*Evidence-based guideline development manual*](https://www.rcot.co.uk/node/293).

# What is the role of a person with lived experience on the Guideline Development Group?

As a Guideline Development Group member with lived experience, your role is to bring your experience of living with dementia or caring for someone with dementia, along with your experience of occupational therapy services to help inform the guideline. We need to know that we are setting recommendations that will have a positive impact, and you can help us to achieve this.

Your role could be one of the following, depending on how much time you have, the skills you bring, and your interest in the guideline topic:

* + **Advisory members** participate in the initial scope meeting (or where we decide what the guideline will include and exclude). They respond when the Guideline Development Group asks for their advice throughout the development process.
  + **Key stage members** participate in meetings at key stages, including setting the scope of the guideline and agreeing recommendations. As with Advisory members, they respond when the Guideline Development Group asks for their advice throughout the development process.
* **Full members** participate in all steps of the guideline process, including screening literature search articles, critically appraising research articles, agreeing recommendations, reviewing the guideline document, reviewing consultation documents and resulting comments, and assisting with promoting the guideline.

You’ll need to do the following no matter which role you’d prefer:

* Attend meetings relevant to your role. These meetings will be online, most likely using Microsoft Teams. We expect to have six meetings while we develop the guideline over an 18-20 month period, but depending on your role, you may not need to come to all of them. The first meeting will take place online on Thursday 9 January 10am – 1pm and will include breaks.
* Input positively to meetings and value all contributions.
* Wherever possible work within agreed timelines.
* Complete a declaration of conflicts of interest form before guideline development starts and update declarations on a regular basis.
* Follow the process described in the [*Evidence-based guideline development manual*](https://www.rcot.co.uk/node/293)(RCOT 2024). We will guide you through this.
* Adhere to RCOT’s  [*Privacy Policy*](https://www.rcot.co.uk/privacy-policy) (RCOT 2019) in line with the General Data Protection Regulation and Data Protection Act.

# What skills and experience do I need for this role?

You or someone you have cared for will need to have experience of occupational therapy and dementia. If you would like to be a full member, you will need some additional skills, particularly in critically appraising research articles. However, don’t be put off if you aren’t confident you have the skills needed for the roles! We want to work with you to tailor the role to you.

See the below table for more information about the experience and skills needed for each role. Please note that for all roles we expect you to live in the UK.

|  |  |  |
| --- | --- | --- |
|  | **All roles** | **Full members** |
| **Experience and knowledge** | * Have experience of occupational therapy for dementia either first hand, or as a carer. * An interest and/or knowledge of producing documents to support best practice. * An interest in the improvement of health and social care, particularly around dementia. |  |
| **Skills** | * Have good communication and team working skills. * Ability to participate in online meetings using appropriate technology, such as a laptop or tablet. * Access and ability to use email. * Ability to maintain and respect confidentiality. * Ability to read professional documents written in English. | * Ability to read journal research articles and critically appraise them. You can find out what critical appraisal means [here](https://casp-uk.net/what-is-critical-appraisal/). * Ability to contribute to and review professional documents written in English. |

We value contributions from all members of society and recognise the historic underrepresentation of certain communities. We strongly encourage people from diverse or historically underrepresented communities to nominate themselves for a person with lived experience role.

# What if I need support to be a Guideline Development Group member?

We’ll ask what support you need to be involved in the Guideline Development Group and try to support your needs within our resources.

# How will I be compensated for my time and expenses?

We will offer you compensation based on guidance from the [National Institute for Research (NIHR) Centre for Engagement and Dissemination](https://www.nihr.ac.uk/documents/centre-for-engagement-and-dissemination-recognition-payments-for-public-contributors/24979) at the following rates:

|  |  |  |
| --- | --- | --- |
|  | Time spent | Type of activity - example |
| **£50** | Approximately two hours of activity. | Face to face or online meeting with related papers to read or review a few short documents. |
| **£75** | Approximately half a day of activity. | Participating in a meeting or panel, participating in a focus group, or delivering training, writing. |
| **£150** | All day meetings/activities. | Taking part in a committee or panel meeting as an active member. Other activities such as writing or delivering training. |
| **£300** | All-day meetings that require substantial preparation. | Chairing or co-chairing a meeting.  Carrying out other discretionary work, which requires additional responsibilities. |

Before each activity we will confirm the compensation rate.

We will cover reasonable expenses to attend meetings, such as:

* travel and subsistence costs
* childcare costs
* carer costs.

For more information, please see our Reward and Recognition Policy on [this web page](https://www.rcot.co.uk/public-contributors).

**What is RCOT’s role in guideline development?**

We will help the Guideline Development Group to follow the guideline development process set out in our [manual](https://www.rcot.co.uk/node/293). We’ll coordinate Guideline Development Group tasks and meetings and provide administrative support. We’ll facilitate the resources needed to develop the guideline (for instance, sourcing research articles to understand the evidence), and will publish and promote the guideline. Finally, we want to make sure that all Guideline Development Group members feel their contributions are encouraged and valued, and that they are supported in their role.

**How do I become a member of the Guideline Development Group?**

If you’d like to become a member of the Guideline Development Group, please complete the self-nomination form and send it to RCOT Research and Development Officer Angie Thompson at [angie.thompson@rcot.co.uk](mailto:angie.thompson@rcot.co.uk) **by** **Friday 29 November.**

You can fill the form in yourself, or you can give your answers verbally and we’ll fill in the form for you. To complete the form verbally, please contact Angie Thompson on 0203 141 4615.

We will review all the self-nomination forms we receive and choose two or three people with lived experience to join the Guideline Development Group. We will let you know the outcome by the Friday 13 December.

Please note the first Guideline Development Group meeting will take place Thursday 9 January 10am – 1pm, online.

**What if I have some questions?**

You can contact Angie Thompson, Research and Development Officer, at: [angie.thompson@rcot.co.uk](mailto:angie.thompson@rcot.co.uk) or telephone 0203 141 4615.