

## **Role description for members of the public and people with lived experience taking part in the development of the Scottish Palliative Care guidelines**

### **Background**

The Scottish Palliative Care Guidelines are designed to support staff across health and social care in providing safe, person-centred care.

One of the most complex and sensitive areas being updated within palliative care is the guidance on managing terminal agitation, which can be very distressing for both the person and those close to them. This can be caused by symptoms such as pain, breathlessness, or emotional distress, and is one of the most complex situations to manage in end-of-life care.

To ensure the language is clearer and more appropriate, this is now referred to as 'Last Days of Life: Severe Uncontrolled Agitation or Delirium'. These guidelines aim to ensure people receive the right care at the right time, while also being clear about the difference between palliative sedation and practices like assisted dying.

Healthcare Improvement Scotland, in partnership with the Scottish Palliative Care Guidelines Steering Group, is reviewing and updating the guidelines to make sure they remain accurate, useful, and reflective of current practice.

We are involving people with lived experience and members of the public to help ensure the guidance is compassionate, clear, and meaningful to those it affects most.

### **Why your involvement matters**

Your voice is vital in shaping care that truly reflects the needs and values of people at the end of life. By sharing your lived experience, you help ensure that the guideline:

- Addresses real concerns of people receiving care and their families
- Reflects what matters most to people receiving care
- Balances scientific evidence with human experience
- Considers the diverse needs of people across age, sex, ethnicity, and background

## **Your role as a group member**

As a lived experience representative or member of the public, you will:

- Attend meetings approximately every 6 weeks
- Share insights on what matters to people receiving end-of-life care
- Help identify areas where care could be improved
- Ensure the guideline reflects the voices of those with lived experience
- Help ensure the guideline is sensitively worded and inclusive
- Participate in reviewing and commenting on drafts
- Take part in consensus voting on recommendations (if applicable)
- Support the consultation and dissemination process

## **Time commitment**

It is hard to say exactly how much time this will take, as it will depend on the subgroup discussions and any follow-up actions. As a rough guide, we expect it to be around 2 hours per week on average. Some weeks may be a bit busier than others, but it should balance out over time. That said, any time you are able to give is genuinely appreciated. We really value your voice - your input truly makes a difference.

## **What you bring to the guideline group**

You don't need formal qualifications. We welcome people who:

- Have direct experience of end-of-life care (for example as a carer, or family member)
- Are passionate about improving care experiences
- Can share views clearly and respectfully
- Are willing to learn about medical terms and processes
- Can represent broader perspectives beyond their own
- Have time to attend meetings and review documents
- Are open to working collaboratively in a group setting

## **Training and support**

There is an induction programme for volunteers. You will also meet the Chair of the guideline group and Programme Manager before you attend any group meetings. You will be supported by our public involvement staff. You are encouraged to get support if you feel unable to carry out a task or need to discuss any aspect of your role.

## **Virtual meetings**

If needed, we can offer support and training on how to join meetings from your computer.

## **Declarations of interest and confidentiality**

You will be required to make a full declaration of interests on joining the group and every year afterwards. We can offer you support on this process.

Please treat all information shared with you in the strictest confidence.

## **Expenses**

We will reimburse reasonable out-of-pocket expenses as a result of your volunteering. We try to limit out-of-pocket expenses by helping book travel and overnight accommodation, where necessary. For those who are entitled to concessionary train travel, and prefer to buy their own ticket, expenses can be claimed. Any expenses claims should be submitted no more than three months after an event.

## **Contact details**

Karen Graham, Public Involvement Advisor

Mobile: 07929027159

Email: [karen.graham2@nhs.scot](mailto:karen.graham2@nhs.scot)