



Meeting - 2 CPG on Carers of people who have had a stroke

Date of Meeting: 14 March 2024

Attendees:

Angela Contestabile, Claire Morgan, John Hunt, David, Judith Rees, Katie Chappelle, Huw Irranca-Davies (MS), Llinos Wyn Parry, Adele Griffiths (Aneurin Bevan UHB - Community Neurological Rehabilitation Service), John Hollies, Sushmita Mohapatra (BCUHB - Therapies & Health Science), Susan Wilson (Swansea Bay UHB - Therapies and Health Sciences), Abdul Seckam.

Summary of the issues discussed:

- The meeting focused on discussing the experiences and challenges faced by carers of stroke survivors, with presentations from various contributors.
- Key themes included the sudden and unexpected nature of becoming a carer after a loved one's stroke, the lack of preparation and information provided to carers, and the emotional and physical toll it takes on them.
- The importance of support for carers, both in terms of practical assistance and emotional well-being, was emphasised.
- The role of the Stroke Association and other organisations in providing resources, advice, and peer support for carers was highlighted.
- Additionally, the need for better identification of carers in healthcare settings and improved financial support was discussed.
- The meeting concluded with a presentation on a new Carers Programme developed by Betsi Cadwaladr Health Board in collaboration with the Stroke Association Wales, aimed at supporting carers from the onset of their caregiving journey.
- The main themes from the discussion revolve around the need for a comprehensive support pathway for carers of stroke survivors. This includes recognising the different needs of carers at various stages, from the

immediate aftermath of a stroke to long-term community support.

- The importance of peer-to-peer support, practical knowledge sharing, and the involvement of carers in influencing and shaping support programs were highlighted.
- There is a call for advocacy to ensure carers' needs are met separately from those of the stroke survivors, with suggestions to engage health boards, the Stroke Improvement Executive, and government officials in the conversation.
- The group aims to use its influence to push for a national agenda that prioritises carer support and education, potentially leading to policy changes and improved care experiences for both carers and stroke survivors.

Please note that this is a summary and may not include all details discussed in the meeting.

A full transcript is available and you can watch the recording of the CPG on YouTube here [**https://www.youtube.com/watch?v=guPByXGllek**](https://www.youtube.com/watch?v=guPByXGllek)