

Cancer Caring Coping: An online resource to support cancer caregivers.

What is it? Cancer Caring Coping is a new online resource made by cancer caregivers for cancer caregivers. This project led by Queen's University was a partnership between Belfast Health and Social Care Trust and The Northern Health and Social Care Trust as well as involvement from the Men's Health Forum In Ireland and Charis Cancer Care.

Why did we start this project? This project was developed based on our previous research which told us that cancer caregivers require specific support and information (Santin et al., 2012, Santin et al., 2015). These earlier studies found that cancer caregivers have poorer health compared to caregivers of other chronic conditions. This current project, in partnership with carers, was an attempt to redress the imbalance by the development and evaluation of a website which aims to provide support and information to cancer caregivers.

What did we do? Through iterative cycles of co-design we have developed a peer led online information resource for cancer caregivers with caregivers. There were five key stages of the project: (1) Development of key concepts with cancer patient and caregiver involvement; (2) Engagement with the Voluntary Sector; (3) Filming and production of the website; (4) Refinement of production (5) Evaluation and subsequent refinement of the website.

What answer did we get? The co-design approach ensured the development of an effective, sensitive and appropriate intervention which appears to be feasible to support the information, emotional and practical needs of cancer carers(www.cancercaringcoping.com).

A total of 55 caregivers completed responses to an online evaluation of which 54 rated the resource as excellent. Caregivers felt that the resource provided useful and relevant information, reduced isolation and uncertainty in the caregiving role. The use of peer lead videos was noted as particularly helpful in terms of providing emotional and practical support. Providing information in the form of peer led videos online was viewed as convenient and less burdensome support than written information, or travelling to access support.

What should be done now? To ensure effective and rapid integration, Northern Ireland Cancer policy and guidelines should specifically focus on plans to meet and respond to the needs of cancer caregivers. Cancer Caregivers report a high level of satisfaction with the resource www.cancercaringcoping.com. Service providers should consider the merit of making the resource widely available to cancer caregivers at the beginning of the cancer journey. Cancer services, general practice and the voluntary sector are key players in the care of cancer caregivers, specific consideration should be given to the development of a training package to assist with the recognition of caregiver needs and the signposting to supports such as www.cancercaringcoping.com.