

**CANCER CARING COPING:  
THE CO-DESIGN DEVELOPMENT AND EVALUATION OF  
AN ONLINE RESOURCE TO SUPPORT CANCER  
CAREGIVERS.**

**Cancer  
Caring  
Coping**



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## **1.0 Evidence Brief: Cancer Caring Coping: The co-design development and evaluation of an online resource to support cancer caregivers.**

**Why did we start?** This Knowledge Exchange Project was developed based on needs identified by carers (n=98), patients (n=289), and health care professionals (n=25) in Northern Ireland (Santin et al., 2012, Santin et al., 2014, Santin et al., 2015). These earlier studies found that cancer caregivers have poorer health compared to caregivers of other chronic conditions and many lack support and information. 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 appropriate and relevant support and information to cancer caregivers.

**What did we do?** Through iterative cycles of co-design between the research team and key stakeholders, we have produced an online information resource developed by cancer caregivers for cancer caregivers. There were five key stages of the project: (1) Development of key issues to be included (with cancer patient and caregiver involvement); (2) Engagement with the voluntary sector to ensure support and resource appropriateness; (3) Filming and production of the website; (4) Refinement of website production; (5) Evaluation and subsequent refinement of the website.

**What answer did we get?** The co-design approach ensured the development of an effective, appropriate intervention which appears to be feasible to support the information, emotional and practical needs of cancer carers ([www.cancercaringcoping.com](http://www.cancercaringcoping.com)). A total of 55 caregivers completed an online evaluation, of which 54 rated the resource as excellent. Evaluation identified that caregivers felt that the resource provided useful and relevant information, and reduced isolation and uncertainty in the caregiving role. The use of peer led 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 a less burdensome support than written information, or travelling to access support services.

**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](http://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 stakeholders in the care of cancer caregivers, therefore specific consideration should be given to the development and evaluation of a training package to assist with the recognition of caregiver needs and the signposting to supports such as [www.cancercaringcoping.com](http://www.cancercaringcoping.com)

## 2.0 Background

One and a half million people aged 16 and over in the UK are caring in the community for a family member or friend affected by cancer (Macmillan Cancer Care, 2016); 48,000 of which live in Northern Ireland (Macmillan Cancer Care, 2016). Informal carers (caregivers) include unpaid carers, people who look after family members, friends, neighbours or others, because of long-term physical or mental ill health or disability (Department of Health, 2016).

Informal carers are vital as they assist in managing medications, symptom management, personal care, social support, and transportation (Macmillan Cancer Care, 2016). Providing informal care can have a negative impact on cancer caregivers' quality of life, physical and mental health. Cancer caregiving has a significant impact on caregivers, with some reporting back and muscular pain, poor sleep and general fatigue (Stenberg et al., 2009), high levels of psychological difficulties such as depression, anxiety, (Braun et al., 2007; Girgis et al., 2013; Mazzotti et al., 2013), intense worry about a patient's health, and stress associated with providing care and support (Hagedoorn et al., 2000; Northouse et al., 2000; Kim et al., 2012). Furthermore, the time and costs of providing care may lead to gaps in, or loss of, employment, reduced income, and overall financial strain (Macmillan Cancer Support, 2016).

Poor caregiver health may compromise their ability to carry out their cancer caring role (Ferrellet et al., 1995; Northouse et al., 2007; Stenberg et al. 2009; Northouse et al., 2012; Santin et al., 2014), and there is evidence to suggest that the health and wellbeing of the cancer caregiver can influence patient health (Hodges et al., 2005). Many cancer caregivers lack information about cancer and the expectations of their role, which can lead to worry and uncertainty (Bevans and Sternberg, 2012). They are rarely adequately prepared, as often this role is unexpectedly put upon them (Macmillan Cancer Care, 2016). Despite the integration of routine patient information in oncology, specific guidelines and supports to best help family and friends to provide care do not appear to be routinely provided (Santin et al., 2014).

The informal care network is vital in the support and care of cancer patients. It is paramount that their health care needs are met to ensure they remain healthy and their caregiver role is not compromised. The current UK health service is devoid of any specific statutory provision for cancer caregivers, with the cancer caregivers reliant on accessing services within the voluntary sector, and professionals feeling ill-equipped to manage caregiver concerns (Santin et al., 2014). It would appear that caregivers require tailored cancer carer-specific information to prepare them to cope with their role.

It has been shown that interventions targetted at cancer caregivers can improve important outcomes such as quality of life and caregiver burden (Northouse et al., 2010; Ferral and Wittenberg, 2017), in particular those interventions utilising technology and a self-directed format (Ferrell and Wittenberg, 2017). In addition, a review of online interventions for caregivers across various chronic illnesses (including cancer), found positive changes in psychological health, knowledge and relationships, however, much of the quality of these studies were deemed as methodologically weak, and therefore more work on the subject is needed (Ploeg et al., 2017).

In response to the rising pressures on caregivers and lack of an obvious solution to the problem, the research team embarked on a project which aimed to explore the health requirements of cancer caregivers and their support needs. This current project, in partnership with local cancer carers, was an attempt to redress the imbalance via the development and evaluation of a website designed to support cancer caregivers in the following ways: provide information on how to cope in the role of carer; reduce uncertainty through peer led resources and provide practical tips and techniques for caregiving.

### **3.0 Aims and objectives**

This project, in partnership with carers, voluntary agencies, Belfast Health and Social Care Trust (BHSCT), and Northern Health and Social Care Trust (NHSCT) aimed to develop and evaluate a website to support cancer caregivers. There were five key stages of the project: (1) Development of key concepts with cancer patient and carer involvement; (2) Engagement with the voluntary sector; (3) Filming and production of the website; (4) Refinement of production with cancer carer and other key stakeholder involvement; (5) Evaluation and subsequent refinement of the website.

### **4.0 Methodology**

This section describes the process undertaken in the development of the website including a description of the conceptual origins, resource development, resource evaluation, and resource refinement. It is important to note that the website was co-designed by cancer patients and caregivers thus their involvement was integral in each of the stages outlined below.

#### **4.1 Stage 1: Development of concept**

This Knowledge Exchange Project was developed based on needs identified by carers (n=98), patients (n=289), and health care professionals (n=25) in both a population based

survey and face-to-face interviews in Northern Ireland (Santin et al., 2012, Santin et al., 2014; Santin et al., 2015). These earlier studies indicated that cancer caregivers had poorer health compared to caregivers of other chronic conditions and many lacked support and information. It is apparent therefore that cancer caregivers require appropriate and specific information regarding managing their role (Santin et al., 2014, Santin et al., 2015).

To further understand the information needs of cancer caregivers, the team was involved in a series of iterative discussions with academics and the Northern Ireland Cancer Research Consumer Forum (NICRCF). This involved three rounds of discussions which led to the identification of the need for a cancer carer specific online resource. Carers and patients identified the need for a resource which focused solely on cancer carers, provided information across a number of domains/stages of illness and included experiences, tips and techniques from peers. This process identified the need for all relevant information available within a single source.

Following this, a Patient and Public Involvement (PPI) event facilitated by the NICRCF was held to develop the nature and content of the resource. This event involved five carers who were representative of the cancer disease trajectory and various caring relationships. In order to support this, we consulted with a cancer care professional, an expert in men's health, a team of academics, and a production team. The early steps allowed us to rigorously develop the website content plan and the overall platform.

#### 4.2 Stage 2: Developing the online resource

The online resource was developed by iteratively integrating the viewpoints and findings from the following:

##### *Stakeholder Meetings*

The development of the resource was supported by a core project team consisting of cancer caregivers, academics, a men's health expert, cancer charities and health care professionals. The team met quarterly to review project progress and iteratively develop the resource at each stage.

##### *Voluntary Sector Involvement*

The project team approached a number of cancer organisations in the voluntary and community sector in Northern Ireland and liaised with them in a series of telephone conversations and face to face meetings. The purpose of this engagement was to promote

the website amongst the voluntary sector; enlist advocacy and support from cancer charities; and recruit carers who would be willing to contribute to the website content. The views and experiences provided by the voluntary sector regarding the resources was feedback to stakeholder meetings.

### *Filming and Production*

The structure of the website was designed and developed by web design experts at the host institution, Queen's University Belfast (QUB).

A media and production company was hired to produce the peer led videos of cancer carers. A total of 15 carers were filmed. Caregivers were interviewed by a film director regarding their experiences of caring across the illness journey. These interviews were then segmented for inclusion in sections which mirrored the various stages of the cancer journey from diagnosis through to bereavement. Six professionals, employed in cancer-related fields also contributed advice and tips for coping in the caring role in video format. These specialists were; a leading cancer surgeon and consultant; a clinical nurse specialist; a clinical psychologist; a senior social worker; a family cancer service co-ordinator; and a fitness and wellbeing co-ordinator.

### *Additional resources*

Through consultation with stakeholder groups, voluntary organisations, health care professionals and cancer caregivers; a list of top tips for caregivers and useful links and resources were also included.

## 4.3 Stage 3: Resource Refinement

Through consultation with the NICRCF and the stakeholder group, a number of refinements were made to the online resource prior to evaluation. These included the development of a website logo, language and structure.

### *Logo development*

A group of ten carers were invited to a workshop held at the School of Nursing and Midwifery QUB, to develop a website logo. A professional Graphic Designer and a CEO of a local arts charity were employed to co-facilitate the workshop. The Graphic Designer, using the ideas and suggestions generated in the workshop developed a selection of logo options for which the group voted via email to reach consensus.



#### 4.4 Stage 4: Evaluation Process

A mixed methods design combining an online survey (accessed via a link contained within the cancer caring coping website) with an optional telephone interview was used for the purpose of evaluation. The team approached caregivers attending 25 outpatient cancer clinics over an eight week period in order to evaluate the resource. Caregivers in the waiting areas were given a personal, one to one demonstration of the website on an iPad and a branded bookmark and pen (designed by carers) with signposting to the site. Participants in the evaluation were encouraged to complete an information needs assessment prior to accessing the website, however uptake for this was low.

Visitors to the website were requested to complete an online demographic questionnaire with optional open ended questions rating the overall look, function and usefulness of the website. The online survey was facilitated by the Qualtrics software which was password protected. Completed surveys were downloaded to SPSS for analysis.

An optional telephone interview was offered which focused on the experiences of using the website, usefulness, impact on information needs and ideas for change. Interviews were conducted until the point of data saturation (i.e. no new themes/topics were emerging from subsequent interviews). All interviews were transcribed verbatim and analysed thematically. This involved the identification of categories and themes in the data, patterns of views, meanings and feelings discussed by the interviewees, and organised in a way that provided meaning to the text. Thematic analysis allows the themes to 'emerge' for the data: themes are not predetermined (as is often the case in content analysis) (Dey, 1993; Miles and Huberman, 1994). Data analytics were also used to measure the number of page visits, website acquisition and most popular sections.

### **5.0 Findings**

#### 5.1 Final Resource

Through the co-design process we developed an online resource ([www.cancercaringcoping.com](http://www.cancercaringcoping.com)) which aims to provide information and advice in the form of peer led videos. This peer led delivery intends to deliver information in a simple and non-technical manner. Each section also included top tips for caregivers and links to signpost to other services.

Co-design demonstrated that the resource should be delivered over specific sections to allow the caregivers to self-select the appropriate information for their current stage in the cancer journey. Health care professionals providing advice on dealing with the emotional impact of caring, financial and employment support and top tips for caring were also included. The individual caring stories and advice from all 15 filmed caregivers were made available to allow viewers to receive more information from caregivers they may have related more closely to.

*Peer led components:*

1: When cancer first came into our lives: This section discusses the common feelings and emotions experienced at diagnosis. Videos provide advice on how to manage: appointments, communication with health care professionals, asking questions, dealing with shock, and managing friends and family.

2: Getting through the treatment: Videos provide peer led advice on; managing and coping with treatment days, managing sickness and eating, medications, interacting with health care professionals, communicating with friends and families and managing questions, accepting help, and taking time for yourself .

3: Caring for yourself: Videos provide peer led advice on; importance of self-care, holistic therapies, coping mechanisms, diet/looking after physical health, spending time with others, and talking.

4: Supporting you to care: Videos provide peer led advice on; accessing help, providing space and time for patient and caregiver, family conflict, normal feelings, reflection, and managing change.

5: Bereavement and life after caring: Videos provide peer led advice on; feelings and emotions, what to expect, managing the grief of others, supports and getting back to routine.

*Professional led videos*

Financial and employment support: This section includes videoed advice from a senior social worker discussing financial, employment and insurance matters, travelling and car parking assistance, financial benefits, financial advisors, and support from employers, talking to employers, returning to work, supporting parents, and occupational pensions.

Emotional Support: This section includes videoed advice from a clinical psychologist discussing emotions, accessing the supports around you, using hobbies and activities, supports and services if things get overwhelming, reducing anxiety and fear, taking time for yourself, and staying in the present, focusing on the here and now.

## 5.2 Website views

The website was created over a period of ten months - from April 2017 to January 2018. From December 1st 2017 - 31st January 2018 there were 461 visits to the website. The majority of time spent by visitors was focused on; financial and employment support (23%), personal stories (22%) and top tips from professionals (22%).

## 5.3 Online Survey Results

A total of 55 caregivers completed the online survey and 7 participated in a follow up interview. Of the 55 who completed the survey, 21 (38%) were male and 34 (62%) female. These participants were caring for 19 (34.5%) males and 36 (65.5%) females. Cancer caregivers ranged from 18 to 75 years of age with a mean age of 45 years and cared for people who ranged in age from 20 to 81 years old with a mean of age of 55 years. The most common type of cancer diagnosed in patients was breast cancer. Other categories of cancer reported were bowel (n=9), gynaecological (n=8), lung (n=6), melanoma (n=5), haematological (n=4), prostate (n=3), pancreatic (n=2), brain (n=2) and eye (n=1).

### *Website content*

As Table 1 shows, the majority of respondents rated all features as excellent or good; with one caregiver rating the relevance of the website as poor.

*Table 1: Cancer Caregivers Response to Cancer Caring Coping Website*

	Excellent	Good	Poor	Terrible
Logo	54	1	0	0
Name	54	1	0	0
Fonts	53	2	0	0
Pictures	54	1	0	0
Videos	53	2	0	0
Tips	53	2	0	0
Links	52	3	0	0
Menu	54	1	0	0
Navigation	54	1	0	0
Relevance	52	2	1	0

#### 5.4 Qualitative Findings

Thematic analysis of open ended responses and telephone interviews identified four key themes: meeting information needs; peer delivery of information; online delivery of information; and negative experience of the resource.

##### *Meeting unmet information needs*

Caregivers perceived the website as a valuable resource mainly due to the perceived current lack of tailored information available to them. Caregivers noted that they often felt ignored within the health care system and that this resource helped to reduce this isolation. Caregivers expressed that prior to accessing the website they felt ill-prepared for caring and that health care professionals' time was focused on preparing patients for the cancer experience. As a result, caregivers were ill-equipped and unaware of what to expect. They reported that the website offered the necessary information needs that in turn reduced their level of distress. The information needs included tips and techniques for caregiving; goal setting; practical and emotional advice about what to expect and what to do; self-care; and where and when to access support.

One caregiver summed up the general positive reception of the website:

*'[I am] very impressed overall. Excellent website, as it focuses entirely on the needs of a carer of someone with cancer. It's important to get the word out there about its existence'* [Carer, open ended response to survey].

##### *Peer led delivery*

The inclusion of caregivers discussing personal examples in videos was said to be very helpful and reassuring. Hearing other caregivers report similar emotions and experiences was reported to reduce feelings of helplessness and uncertainty surrounding cancer and the caregiving role. Cancer caregivers reported that they found the experiences of peers motivating and inspiring. The use of peer led videos was particularly helpful in terms of providing emotional and practical support, caregivers felt that the tips and techniques could easily be implemented in day to day life and make a positive impact.

Caregivers reported that they could relate to the peer led information and felt a sense of receiving one to one support. The use of real life experiences was described as de-isolating and reassuring which in turn helped caregivers to feel less alone. Several carers identified in this regard:

*'Sometimes I feel so alone and confused. I feel helpless. It really helped hearing that I'm not alone and that other people feel the same'* [Carer, telephone interview].

### *Online delivery*

The use of an online delivery mechanism was viewed positively by all cancer caregivers. Caregivers reported that absorbing information in written form whilst caring for someone who has cancer can be very challenging due to limited personal time and high emotions which can make it difficult to concentrate to read. Providing information in the form of online videos was viewed as convenient and less burdensome than reading. Caregivers reported that the online film format allowed them to receive tips and advice in a faster and more expedient way. This was viewed to be beneficial to all, particularly those who lived in rural areas. Caregivers also felt that the website was easy to use due to the clear layout and straightforward access to relevant information. The themed sections also appealed to carers as they gave ease of access to specific supports without the need to read irrelevant material:

*'[I liked the] easy access to information ... It was set out in sections that allows everyone to reference depending on their caring situation'* [Carer, telephone interview].

### *Negative experiences*

Three people who responded to the open ended questions reported a more negative experience of using the website. Two felt the resource did not represent male caregivers or families with younger children. As a result of these comments changes and adaptations were made, including further video footage. These changes involved the inclusion of specific videos focused on caring when families have young children; we also included additional video footage of male carers. Regrettably, one person stated they found that listening to other people's experiences lowered their mood and as a result they left the website. The developers recognise that this resource will not suit everyone.

A number of caregivers suggested that the website would benefit from an interactive function to facilitate and moderate questions, answers, debates and general communication with an online support group of cancer caregivers. Caregivers expressed that having the opportunity to interact directly with other caregivers would provide an additional layer of support and information.

*'I'd like to be able to chat with other people facing similar issues as my family so it would be good if there was a live chat facility ... Maybe a way to post questions and chat with other people who have a loved one with cancer so that we can support each other'* [Carer, telephone interviews].

This point was considered by the steering group, however it was felt that in the absence of staff to monitor the website and answer questions posted, it would not be advisable to build this function in at present.

## **6.0 Conclusion**

Through an iterative co-design process, a website was developed to provide information to cancer caregivers in the form of peer led videos. Evaluation of the resource was very positive with the majority of caregivers rating the resource as excellent. Caregivers reported that the resource provided useful information which helped to normalise emotions and provide information on what to expect in the caring role. The positive response to the resource supports the use of co-design as a mechanism to identify and implement improvements in health care, supporting the view that users' experiences can be improved by listening to the views and opinions of those who use the service. The co-design process ensured that the website was aligned with the population needs (Cosma et al., 2015), and the evaluation demonstrated that this was indeed the case.

According to the respondents, using peer led videos and listening to the experiences of real life caregivers reduced feelings of isolation, provided emotional support, and reduced feelings of uncertainty. There is a strong body of evidence regarding how narratives can meet the needs of people affected by cancer. Narratives can allow experiences to be normalised by developing understanding and meaning and thus reducing uncertainty and promoting coping (Carlick and Biley, 2004; Kreuter et al., 2007). People communicate with one another and learn about the world around them largely through stories, which is a comfortable way of giving and receiving information (Carlick and Biley, 2004; Kreuter et al., 2007). This evaluation suggests support for this ethos, suggesting that peer led information may be an effective and alternative information provision to costly HCP led supports. Reviews of interventions targeted to cancer caregivers have demonstrated that the majority are HCP interventions focused on psychoeducation, skills training and therapeutic counselling (Northouse et al., 2010; Ferrell and Wittenberg, 2017). Given the rising number of cancer caregivers and strain on current available resources, future research should examine the feasibility and effectiveness of peer led supports.

The web-based format of the resource was viewed positively by caregivers due to the ease of access and no geographic or time barriers.

A recent review of online interventions for cancer caregivers suggested that web-based interventions can improve coping, psychological wellbeing, burden and perceived bonding between cancer caregivers and patients, however many of these studies have methodological issues. Further high quality research is required to rigorously test the effectiveness of online interventions. There is a growing recognition that involving patients and caregivers in service development and specifically cancer services is beneficial and influential. This report supports that view and provides an example to equip providers to work in partnership to improve supports (Tsianakas et al., 2012).

In conclusion, the co-design approach ensured the development of an effective, sensitive and appropriate intervention which appears to support the information, emotional and practical needs of cancer carers. We recommend that service providers consider the merit of providing cancer caregivers with access to the resource [www.cancercaringcoping.com](http://www.cancercaringcoping.com) in order to meet their information needs and sign post to support services.

## **7.0 Practice and policy Implications/Recommendations**

### **Implementation**

1. Cancer caregivers report a high level of satisfaction with the resource [www.cancercaringcoping.com](http://www.cancercaringcoping.com). Service providers should consider the merit of making the resource available to cancer caregivers from the beginning of the cancer journey.
2. To ensure effective and rapid integration, policy and guidelines should specifically focus on plans to meet and respond to the needs of cancer caregivers.
3. To ensure ease of implementation, project resources include a Cancer Caring Coping pen and bookmark. These resources will ensure that HCP's can signpost cancer caregivers to the resource in a simple and effective way. However, further funding will be required to purchase more of these for the long term future of the website.
4. General Practitioners are often the gatekeeper to provide support to cancer caregivers. Cancer Caring Coping should be made available to all general practices throughout Northern Ireland.
5. The voluntary sector provides the majority of support to cancer caregivers in Northern Ireland. Links and information should be sent to all cancer specific voluntary organisations in Northern Ireland.
6. To ensure the long term support for this website it is important that the site is incorporated in a web space that is connected with the health service.
7. The implementation phase of the current website should be evaluated to ensure adequate uptake and usage.

### **Future development**

8. Involving patients and caregivers in service development and specifically cancer services is beneficial and influential.
9. A main recommendation suggested by carers was that in future the resource should consider the inclusion of an interactive feature to allow for open discussion with other cancer caregivers.
10. Future resources should consider including more practical tips for what to expect when visiting the cancer clinic presented in a virtual tour of units and treatment centres.
11. Future resources should consider including further information on benefit entitlement.
12. Future resources could consider the inclusion of a needs based assessment to enable carers to be directed to the information they need.



- 13.** To assist with implementation HSCTs and voluntary agencies should consider the wider application of caregiver assessments and sign posting to relevant services.
- 14.** Future resources should consider extending [www.cancercaringcoping.com](http://www.cancercaringcoping.com) to young carers and also those who care for children who have cancer.

## **8.0 Pathway to Impact**

### *Clinical Impact*

Earlier studies in Northern Ireland have found that cancer caregivers have poorer health compared to caregivers of other chronic conditions and many lack support and information (Santin et al., 2012; Santin et al., 2014, Santin et al., 2015). Cancer caregivers require appropriate and specific information regarding managing their role.

The online resource [www.cancercaringcoping.com](http://www.cancercaringcoping.com) provides an effective and rapid way for cancer services to meet the needs of cancer caregivers by providing the promotional pen or bookmark to cancer caregivers at the diagnosis appointment. By providing access to the website from the first diagnosis consultation cancer carers will be prepared for the caring role and will be signposted to other supports.

### *Policy Impact*

Many cancer caregivers lack information about cancer and the expectations of their role, this can lead to worry and uncertainty. They are rarely prepared, as often this role is unexpectedly put upon them (Santin et al., 2014). Despite the integration of routine patient information in oncology, specific guidelines and supports to best help family and friends to provide care are not routine. Cancer policy must recognise this need and include robust plans and supports to meet the needs of cancer caregivers.

### *Educational Impact*

To ensure rapid implementation into clinics, a training package should be developed and evaluated to ensure that all staff involved in cancer care is aware of the needs of cancer caregivers and the resources available, including [www.cancercaringcoping.com](http://www.cancercaringcoping.com) and other support services.

### *Sustainable Impact*

The e-platform for knowledge exchange will enable sustainability and future-proofing as resources can easily be updated and uploaded. The website is currently hosted and content managed by QUB, therefore allowing for continuous updates by the research team and partners. It is envisaged that following the website will be hosted by the Northern Ireland Cancer Network (NICAN). The team is in the process of getting agreement with the HSCTs and various voluntary agencies that they will make available a link to the resource via their website. The website is mobile enabled thus allowing access on various devices.

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