

## Highlights of an evaluation report for the first 12 years of the Solaris Carers Course

**Title:** Providing support to family carers for 12 years: Thoughts amongst carers towards the carer education workshop at Solaris Cancer Care.

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### Background

The carer education workshop has been offered through Solaris Cancer Care support centres for the past 14 years. The central venue and weekend schedule meant ease of access for many carers in terms of familiarity of surroundings, generally fewer work commitments and easier parking than busy hospital weekdays. All three facilitators delivering the workshop have a broad knowledge base of health care services, encompassing acute and oncology nursing, psychology and accredited complementary therapy.

The group was convened in a supportive atmosphere and carers were gently encouraged to participate and to share with both conveners and other carers around their experiences of caring for someone with cancer. The choice of support centre for a venue meant that the atmosphere was one of soft lighting and comfortable seating with trained support staff on hand. This course is part of the resources offered at the centre, and is described as a carers course for those supporting a family member or friend with cancer. Although the course seeks feedback from those attending and all has been collated, it was not until 2018 that the feedback from attendees since 2007 was further analysed by a team of researchers and the course manager. This was utilised to provide a quality assurance mechanism to ensure that the course was delivering the best available information and support to attendees.

As everyone reading this article is aware, family members often experience challenges when supporting someone with cancer. Regardless of circumstances, the impact of being a carer can affect both physical and emotional wellbeing of carers. It has been identified that one of the key issues is a lack of certainty around how to care for the person with cancer as well as how to cope with a number of issues such as communicating with the health care system, coping with the uncertainties of the cancer trajectory and taking care of oneself as a carer. Furthermore, the carer may often be dealing with their own emotional issues around the diagnosis of a partner or close family member and fear of the future. Understandably, the focus is on the patient treatment and management of side effects and thus meeting the needs of family carers can be undermined or minimised. Compounding the issue is a lack of time to participate in regular support group meetings or accessing accurate information online.

The workshops were evaluated at the end of each session by short evaluative survey comprising a number of open-ended questions. The results of these responses are presented here and demonstrate the overall value of this course which is reported to be non-judgemental, informative and supportive resource for carers of persons with cancer. In terms of those who responded, they self-reported as caring for a person (most often a family member) who had been diagnosed with cancer and for whom they were in an informal caring role. Overall, more than 458 carers responded to the questionnaire. The majority were female (79%) and the mean age was 57 years.

### **What carers said.....**

Primarily carers believed that attending the course would enable them to be better prepared for the future and that by attending the course it would enable them to “become a better carer”.

#### *Preparing for the future - becoming a better carer*

Although some felt that they faced an uncertain future in terms of their significant other and their health, they also hoped that attending the course would better help them to prepare for this.

**“Knowledge and confidence to face the future.”**

Overarchingly, many carers stated that they “just wanted to become a better carer”. One person described this as,

***“Filling in the gaps, taking on new ideas and realising weaknesses to work on. How to be a good carer and what help there would be for carers.”***

#### *Understanding the patient perspective on their illness*

Another key theme centred on the importance of understanding the patient perspective or “knowing what the patient is going through”. This could be in terms of changes to brain chemistry such as changes influenced by chemotherapy regimens [*“Understanding the cancer patient behaviour and changes (my wife and chemo)”*] and also in terms of more psychosocial patient challenges [*“How to understand what mum is going through and how to support my family”*].

**“A better understanding of the cancer journey.”**

#### *Seeking knowledge and advice*

Carers also highlighted the importance of practical advice and knowledge to help support themselves and the patient. One termed this as, “a stronger information base”. It was also mentioned that gaining greater confidence in terms of initiating information seeking was valuable,

***“Provides confidence in seeking information when needed.”***

Providing balance between practical information and ‘empathy and understanding’ was highlighted by carers. One wrote:

***“Wonderful to give a format that gives practical and informative knowledge as well as empathy and understanding – thank you.”***

Some carers who had been providing support for longer also highlighted the importance of becoming aware of ‘new’ or ‘different’ techniques to provide care. Others said that they had gained extra information regarding resources that they had not been aware of previously. Others noted that they had learned about specific resources through attending the course. These were primarily information on medications, nutrition and palliative care.

### *The support of other carers and group participation*

One other aim of attending the course was to meet other carers for support and sharing of experiences. A number of carers spoke positively of this experience. Others described it as a 'wonderful opportunity to share yourself with others' and that it was about 'meeting people experiencing similar situations' and 'mateship'. Other carers highlighted the importance of connection with other carers and meeting others 'with a similar outlook'. For some carers, meeting other carers enabled them to gain new knowledge about how to care for someone whereas for others, they felt reassured that others were going through similar issues to themselves. One participant described this as follows,

***"A sense of connectedness, through diverse stories from carers. A place to come, to contact and to let go."***

Many carers found the group format a positive experience with some recognising that other carers had more challenging circumstances and also that hearing other participant stories enabled them to 'learn something new'. As one participant explained,

***"Each person and their stories opened a world."***

Most found that the group dynamics were 'good' and 'non-threatening'. Words used to describe this were, 'relaxed', 'safe environment' and 'supportive'. Others described the 'open atmosphere of the group' and the 'positivity' and warmth of other carers and presenters which one noted as 'easy to be included'.

***"While obviously everyone has emotion and pain to deal with the ability of attendees to share experiences I appreciated much."***

One participant said that they felt, 'confident and recharged'. It was also a positive that the 'ground rules were set at the outset.' Others valued the chance to 'be listened to' within a small and 'secure' group setting.

***"Great to share with others and know they are also going along the same journey with the same questions. I don't feel so isolated."***

There was reassurance in knowing that other carers were facing similar challenges and the ability to listen to other participant stories brought encouragement to many carers. One termed this as finding comfort in 'knowing that you are not alone out there' and one spoke of the 'camaraderie' in the group which, "Sort of unified a group of strangers brought together by cancer."

### *Who cares for the carer?*

Many carers spoke of the aim in attending the course to learn how to take care of themselves as a carer or to 'renew one's spirit' as one carer termed it. This was often within the context of being able to then provide better care for the care recipient. As one termed this,

***"How to make time for self-care during a challenging period."***

Most recognised the importance of self-care as a carer using phrases such as 'self-preservation' and 'it is vital'. Others learned how to take 'time out' for oneself as a carer and another to balance between self-preservation and responsibilities as a carer.

***"Awareness of self-preservation and responsibilities as a carer – widen exposure to support and issues faced – find some strategies or confirmations to assist me."***

Some of the carers highlighted the need for support and advice in dealing with their own emotions and at times those of the care recipient.

***"To learn more skills in how to communicate and manage emotional both mine and those of the person I am caring for."***

Another reason for attending the course was around seeking **validation** in terms of their knowledge and abilities to care for the care recipient. In other words to know, as one put it, "I am on the right track". Others termed it as finding reassurance that what they are doing is correct and to give them courage,

***"To be more assertive, reassuring of how I am caring for my husband."***

### *Gain new information*

Overarchingly, gaining new information was often mentioned and highlighted by carers. One person noted that the handouts and information were clear and very applicable to a specific situation. Others felt that they had learned new information by attending the course. One commented,

***"I have learnt more from today than I have in 27 years as a carer."***

### *Feeling secure and supported*

One person spoke of the fact that they had gained greater confidence from attending the course. Another said that it was a very supportive learning environment and the presenters were 'very caring'. Others spoke of the supportive atmosphere and that they felt supported by both the course facilitators and other carers who were also attending. Carers felt that in some ways they already knew some of the issues around caring but that, in balance, they learned a great deal of new strategies to cope with the role of caring. One participant appreciated the fact that the course had taught her that she will have times when it is important to acknowledge that she cannot manage alone.

***"It made me acknowledge that there will be times when I cannot focus and manage."***

Some valued the role that the Solaris carers course had played in making them feel confident and supported. For some, it was also having the course facilitators and other carers empathise with them.

***“Thank you so much for a day filled with helpful information, sensitivity and group discussion.”***

Others noted that ‘it is good to share’ in helping ease anxieties and concerns. The access to help and to information was valued as was the course ability to help carers face some significant issues. One participant termed to course content as, ‘practical and informative knowledge’.

#### *The benefit of new knowledge*

Some carers spoke of the benefits of new knowledge that they had gained from attending the course. Specifically practical tools such as keeping a diary, medications card, the expected duration of pain amongst others. Additionally, carers noted that the tips and advice had ‘helped me lots’ and that they had gained a better understanding of cancer and strategies to cope with symptoms and side effects. One commented,

***“Overall I found the whole session a great learning curve and useful in a practical way.”***

Some carers commented that the course was very informative and that for some, although already providing care for a significant other that there is,

***“Always something to learn.”***

Another said that although they were familiar with some aspects often course that it was important to ‘relearn’. One participant had valued the ability to be able to ask questions of the presenters and that the subject matter had been very ‘comprehensive’.

#### *In summary*

Over the course of 14 years, the carers’ education course has evolved. However, the open-ended responses to the evaluation of the course demonstrate that there are some core values that sustain the course’s effectiveness and popularity and also provide a number of support mechanisms for family or informal carers of someone with cancer. Carers mostly enjoy support of other carers, education in a practical sense but which is nonetheless supportive, non-judgemental and addresses the necessity of balance between carer role and taking care of oneself both physically and emotionally.

