

# HOW TO IMPROVE ACCESS TO SUPPORTIVE CARE FOR CANCER PATIENTS?

# The EXPERIENCE of ROSE UP ASSOCIATION

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# Introduction

RoseUp is a non-profit patient association founded in 2011. Its three missions are to inform, support and defend the rights of women affected by all types of cancer, from the moment the disease is diagnosed, through to treatment and beyond.

In the context of outpatient care and hospitalization at home (HAH), we need to imagine new ways of improving the quality of life of women with cancer. To this end, the association has devised the concept of the 'Maison RoseUp' (RoseUp Homes) based on the needs of patients, with both in-person and online access attendance, using a multidimensional approach.

#### The missions of RoseUp **Association**



The 3 Maisons RoseUp offer free access to a wide range of supportive care workshops run by carefully-selected professionals trained in cancerrelated issues. Support care is offered on a variety of themes, either faceto-face or online, to help women understand their illness, learn about their rights and cope better with the side effects of their treatments (socioaesthetics, adapted physical activity, nutrition, art therapy, rights and assistance, etc.).

All programs offered to women are validated by a scientific committee made up of oncologists, gynecologists, oncology researchers and oncology nurses.





The support provided online, called M@ Maison RoseUp, offers:

Webinaires, small group workshops and individual meetings



A hotline with a dedicated contact person



M@ Maison RoseUp - RoseUp Association (rose-up.fr)

Personalised support tailored to each individual's needs and desires



# **Objectives**

How does the specific support offered by Maison RoseUp help women affected by cancer?

Two social impact studies assessed how they appreciate the support offered, whether this support was given in-person, online, or on a mixed-use basis.

# **Methods**

- Qualitative component to assess the Maison RoseUp: 8 semi-directive interviews with 13 beneficiaries, 5 professionals (Rose Up staff, support workers) and 6 non-participant observations.
- Qualitative component to assess the M@ Maison RoseUp: 8 interviews, 3 focus groups (7 beneficiaries), 6 professionals.
- Quantitative component by questionnaire distributed online to members between 19 June and 12 July 2023:
- 441 respondents, 28% response rate, 95% confidence interval 109 in-person, 155 mixed-use and 177 exclusively online.

# Results

On average, the women supported are young and professionally active.

Characteristic	Maison RoseUp	M@ Maison RoseUp
Median age, years	54	54
Employed at diagnosis	70%	77%
Currently employed	26%	30%
Frequency of use <ul><li>Once a week or more</li></ul>	27%	24%
<ul> <li>Once or twice a month</li> </ul>	26%	33%
<ul> <li>Less than once a month</li> </ul>	20%	35%
<ul> <li>Don't know or not using</li> </ul>	27%	7%

**Table 1. Participants' characteristics** 

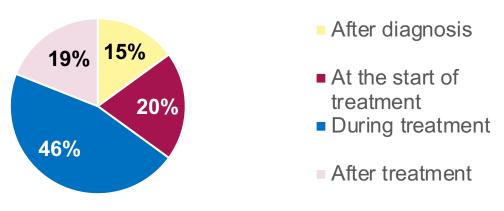


Fig 1. Timeframe for joining the patient association

# 4 major impacts

# 1- Improved physical and psychological well-being for 60% of women

RoseUp association offers a warm and caring environment where women are recognized as women, not patients. The range of activities on offer promotes both physical and psychological well-being in the short and medium term.

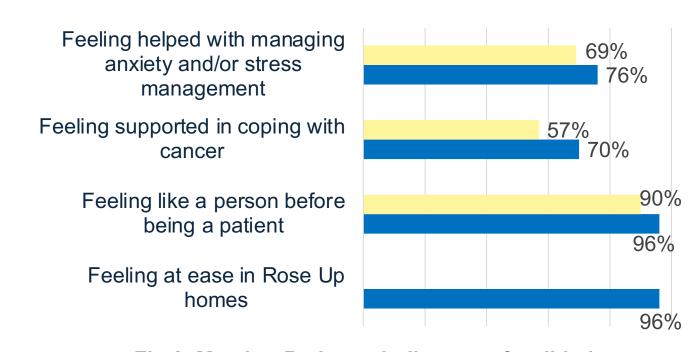


Fig 2. Member Ratings: Indicators of well-being



# 2- Increased ability to assert their rights and make their own personal choices in the care

Members have access to clear, reliable information that is useful to them in their care. They are better able to take ownership of their care pathway and assert their rights and personal choices.

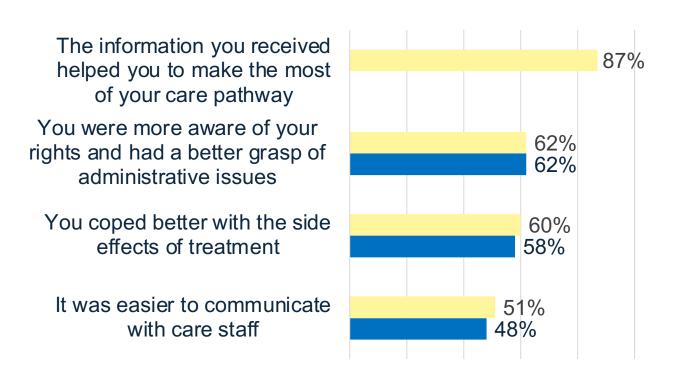


Fig 3. Member Ratings: Empowerment in the care pathway

# 3- Preservation and reinforcement of social life: much greater impact in face-to-face sessions

RoseUp enables its members to share collective experiences and break out of their isolation despite the distance. The impact on social links is still limited online.

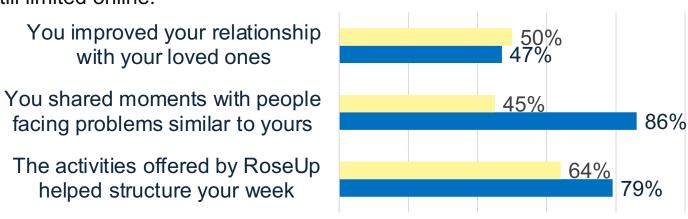


Fig 4. Member Ratings: Social Connection Quality Scores

# 4- Facilitation of their professional future

RoseUp offers a specific program, "Rose coaching emploi" (Rose Job Coaching), to help women deal with the difficulties of employment as cancer patients, and to help them redefine their relationship with work. 86% of respondents who had taken part in at least one employment workshop said that the Maison RoseUp made it easier for them to continue/return to work, compared with 18% of those who had not.

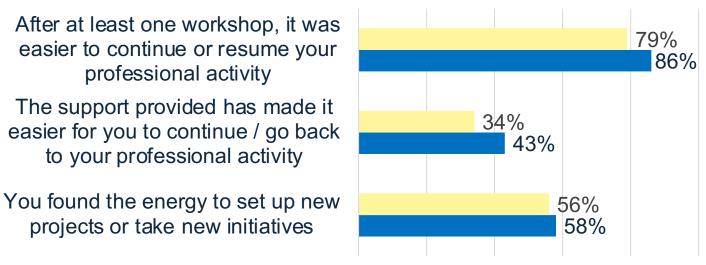


Fig 5. Evaluation of Work-Life Facilitation

### Conclusion

Support and information are major issues for women affected by cancer. RoseUp's expertise in this field shows that the earlier women are supported in their life and care journey, the better their quality of life will be during treatment.

The RoseUp homes contribute to improving the quality of life of women affected by all types of cancer. Flexible schedules, non-mixed locations, a multitude of supportive care workshops, guidance from professionals and the possibility of either face-to-face or remote use are all conducive to a wide range of benefits. These include a better understanding of the illness, support with managing the side effects of treatment, feeling less isolated, making it easier to return to work, and enabling women to maintain their full place in society despite their illness.